DOCUMENT RESUME

ED 407 773 EC 305 529

TITLE	TIPS: Trends for Inclusive Pediatric Services.
INSTITUTION	Connecticut Univ. Health Center, Farmington.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE	[97]
NOTE	103p.; Appendix F of "Physicians Training Project. Final Report," see EC 305 526.
CONTRACT	H029K20361-94
PUB TYPE	Guides - Non-Classroom (055)
EDRS PRICE	MF01/PC05 Plus Postage.
DESCRIPTORS	Community Services; Cultural Differences; Delivery Systems; *Disabilities; Early Childhood Education; *Early Intervention; Educational Legislation; Elementary Secondary Education; Family Programs; Federal Legislation; Inservice Education; Interprofessional Relationship; Medical Education; *Medical Services; Pediatrics; *Physicians; Records (Forms); Referral; Self Evaluation (Individuals); *Special Education
IDENTIFIERS	Case Management; Connecticut

ABSTRACT

This guide was developed as part of a project to provide practicing physicians with training to enhance their understanding of and involvement with early intervention and the special education system in Connecticut. The introductory section notes that best practices in both primary medical care and early intervention promote care that is family centered, community based, comprehensive, collaborative, coordinated, continuous, and culturally competent. The following nine sections provide information on: (1) laws pertaining to children with disabilities; (2) family-centered health care; (3) cultural competence; (4) care coordination and the medical home; (5) communicating with families; (6) collaboration and alliance building; (7) procedures for early intervention referrals; (8) community involvement; and (9) tools for enhancing care. A self-check section encourages self-evaluation, reflection, and application of the material. Attached is a set of sample forms to assist in tracking and coordinating services. (Contains 45 references.) (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED 407 773

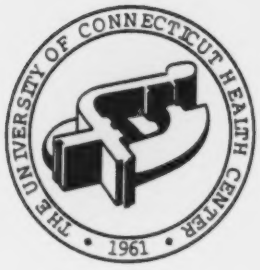
TIPS:

Trends for Inclusive Pediatric Services

EC 305 529

BEST COPY AVAILABLE

University of Connecticut Health Center
Department of Pediatrics
Division of Child and Family Studies



TIPS: Trends for Inclusive Pediatric Services was developed by:

The Physicians Training Project

Project Director: Mary Beth Bruder, Ph.D.
Project Coordinator: Stephanie G. Begen

For information or additional copies, please contact:

Division of Child and Family Studies
Department of Pediatrics
University of Connecticut Health Center
Suite A200 - Farm Hollow
309 Farmington Avenue
Farmington, Connecticut 06032
(860) 679-4632

The Physicians Training Project is funded as a model demonstration grant from the U.S. Department of Education, Office of Special Education Programs, Division of Personnel Preparation. Grant #H029K203.

Table of Contents

I. Introduction and Objectives..... i

II. Laws Pertaining to Children with Disabilities..... 1

III. Family Centered Healthcare..... 13

IV. Cultural Competence..... 21

V. Care Coordination and The Medical Home..... 25

VI. Communicating with Families..... 33

VII. Collaboration and Alliance Building..... 43

VIII. Procedures for Early Intervention Referrals..... 51

IX. Community Involvement..... 62

X. Tools for Enhancing Care..... 70

XI. References and Resources..... 89

TIPS:

Trends for Inclusive Pediatric Services

Physicians and other healthcare providers are often the first people parents speak with when they have concerns about the development of their children. Thus, the healthcare provider is often the critical entry point for families to access information, resources, and services designed to enhance a child's development in all realms. Meeting the needs of children with disabilities or special healthcare needs is a complex process for all involved. It requires highly refined skills in communication, cooperation, coordination, and collaboration. These collaborative efforts must involve parents, other family members, primary care physicians, other healthcare providers, and other service providers in a close partnership. When fully realized, alliances and collaborative efforts enhance the care provided to children and improve the outcomes for children and their families.

Physician training, as well as training in other human services fields, is beginning to incorporate a more comprehensive, coordinated, system-based model of care that defines how services should be provided within the context of the family's needs. The principles of family centered care and cultural competence are key in this approach. Parents should be viewed as the ***experts*** regarding their children, because they are. Their input must be valued as essential for providing appropriate care that recognizes the family's unique role. Parents provide the bulk of direct care, advocacy, and coordination of services for their children. For this reason, parents need to be supported in their natural care giving roles by being fully informed and respected as active decision makers. When parents feel valued and competent, they become more effective in caring for their children. For those who are willing to listen and learn,

"... a large part of the answer to the problems of parents and professionals working together lies within each person - in eliminating his or her own insecurities, honing their own skills, raising their self-assuredness, and increasing their self-esteem to such a level that others will say of us, in this day and time, that the only thing that exceeds our competence, our compassion, and our caring is our ability to collaborate."

R. B. Darling & M. I. Peter (1994)

parents can be excellent teachers, offering healthcare and service providers valuable information about their experiences with and knowledge of their children.

The role of the primary care physician is expanding in many ways. A shift in paradigms is occurring from the purely clinical or biomedical perspective to a model that emphasizes a social systems or biopsychosocial perspective. In 1978 the APA task force indicated the need for physicians to gain skills for:

- providing care to children with biosocial and developmental needs.
- improving interpersonal and professional approaches toward children with disabilities and their families.
- improving and increasing participation on inter-disciplinary teams.

Best Practices

- *Family centered*
- *Comprehensive*
- *Coordinated*
- *Collaborative*
- *Community based*
- *Continuous*
- *Culturally competent*

In addition, physicians need to be aware of the variety of problems and risk factors for children, i.e. illness, disease, developmental delays, and behavioral difficulties. Biological and environmental risk factors that may cause developmental delays or disabilities need to be considered as well. Helping family members adjust to and live with their child's difficulties is increasingly part of the continuum of pediatric services along with prevention, health promotion, well child care, acute condition care, treatment, and rehabilitation. Thus, healthcare providers need information about the resources, supports, and services available to families. It is the responsibility of healthcare and service providers to assure that services are coordinated, complimentary, and consistent. A well integrated network of services addressing the total needs of the child and family is essential.

There are a number of barriers to providing effective and comprehensive care to children with disabilities and special healthcare needs and to their families. Services are often fragmented due to a lack of communication and coordination among healthcare and service providers, as well as with the family. Roles, responsibilities, and expectations may not be clearly defined and individual efforts may not be efficiently coordinated or managed.

Several key concepts are associated with best practices in both primary care ***and*** early intervention philosophies and practices. These promote care that is family centered, community based, comprehensive, and collaborative. To this end the **Family-Physicians Alliances Project** is an effort to enhance relationships between parents, physicians, and other healthcare providers. In the spirit of building alliances, **TIPS: Trends for Inclusive Pediatric Services** has been developed. Family members of a child with disabilities or special healthcare needs have been asked to share this booklet with you. Our hope is to encourage these partnerships by offering physicians and other healthcare providers information that will be useful in caring for children and supporting families in family centered, comprehensive, coordinated, and collaborative ways.

Who We Are

The Division of Child and Family Studies, part of the University of Connecticut's Department of Pediatrics, administers numerous state and federal grants. These grants provide funding for research, demonstration, and training projects that offer service, support, resources, and materials to personnel from a variety of agencies and disciplines, as well as to families who have children with disabilities or special health care needs.

The mission of **The Division of Child and Family Studies** is to design, develop, and evaluate family centered, comprehensive, collaborative, and community-based service delivery systems that will enhance the development of infants and children who have disabilities and/or chronic illnesses. In support of this mission, the Division of Child and Family Studies is administering a special projects grant, known as the Physicians Training Project. The purpose of this grant is to provide practicing pediatricians, pediatric residents, and medical students with information regarding their role in Connecticut's early intervention and special education systems.

Objectives

It is our intention that the readers of **TIPS: Trends for Inclusive Pediatric Services** will:

- Gain an understanding of the specific components of laws pertaining to children with disabilities, ages birth to 21, and their families, particularly the Individuals with Disabilities Education Act and its provisions for children ages birth to three.
- Gain awareness of skills required to apply the nine principles of family centered care.
- Increase understanding of the value of cultural competence and skills for working with those who are "culturally different" in the broadest sense of the word.
- Gain skills for providing coordinated care to children with disabilities and special healthcare needs and their families.
- Gain understanding of communication practices that are supportive to families and that help family members identify their concerns, priorities, and resources.
- Gain understanding of the benefits of collaboration and alliance building and the skills to do this effectively.
- Understand the advantages and procedures for referring families to early intervention programs, and the physician's role in providing services to children ages birth to three.
- Gain an awareness of ways to maximize community based resources and support systems for children and families.
- Be able to employ tools that make office procedures more efficient for children with disabilities and special healthcare needs.

Finally, it is hoped that readers of **TIPS** will provide ***comprehensive, coordinated, continuous, collaborative, family centered, community based, and culturally competent*** care to children with disabilities and special healthcare needs and their families.

Feedback

In the pocket inside the back cover of **TIPS**, you will find a large postcard which asks for your feedback about this booklet. We would very much appreciate your completing this evaluation form and returning it to us at your earliest convenience. Your response is important to us as we plan further projects that support families and physicians working together in caring for children with disabilities and special healthcare needs.

TIPS

Laws Pertaining to Children with Disabilities

The **Individuals with Disabilities Education Act** (**IDEA**, P.L. 101-476) guarantees that all children with disabilities, ages birth to 21, have a right to a free, appropriate public education. A description of the five underlying premises of the Individuals with Disabilities Education Act (IDEA) follows.

The Zero Reject Principle

A free, appropriate public education is guaranteed for all children ages 3-21 regardless of the severity of the individual's disability. Children under three may be provided services if state law, regulation, or judicial ruling mandate them. In Connecticut, services are currently provided to children under age 3 through Part H of IDEA.

Nondiscriminatory Assessment

A multidisciplinary team must conduct an evaluation in the child's primary language or mode of communication, using observations and non-biased, validated instruments. The child must be evaluated in all areas related to the suspected disability. The assessment should allow the child to display his or her capabilities and strengths, as well as his or her needs and difficulties.

Individualized Education Plan (IEP)

An appropriate Individualized Education Plan must be written for each child. This legal document should be developed during a team planning meeting composed of parents, a school administration representative, the child's teacher, members of the evaluation team, and others (such as a physician) invited by the parents or the school. The IEP will contain a statement of the child's

current level of performance; long term goals and short term objectives; specific educational services the child will need; the date for beginning services, and the anticipated duration of the services; the extent of the child's participation in the regular or mainstream education program; and how to determine whether the goals and objectives for the child are being met.

Least Restrictive Environment (LRE)

To the maximum extent possible, schools must educate children who have disabilities with their peers who do ***not*** have disabilities. To provide the Least Restrictive Environment for children:

- Special classes, separate schooling, or otherwise removing a student with disabilities from regular education should occur only when the nature or severity of the disability is such that education in regular classes cannot be achieved satisfactorily even with the use of supplementary aids and services.
- Schools must provide a spectrum of placement options (regular classes, regular classes with minimal support, regular classes with one-to-one assistance, special education classes, etc.), and supplementary services (adaptive physical education, speech and language, etc.).
- Schools must provide education as close to the student's home as possible, and allow a student to participate in extracurricular and nonacademic activities to the extent appropriate.
- The school must work to return a child with disabilities placed outside of the regular education classroom back into the regular classroom as soon as possible.

Due Process and Parent Participation

School districts must establish and follow specific procedures in order to protect the rights of children and their families. Due process procedures must include the following components:

- Parents may examine all records pertaining to their child.
- Parents have the right to obtain an independent evaluation of their child, in addition to that provided by the school district and its staff.
- Parents must be given the opportunity to consent or object to the identification, evaluation, or placement of their child. They must be informed of the team planning conference and encouraged to participate. Meetings must be scheduled at times convenient for parents and appropriate communications must be maintained with them.
- Parents or guardians must receive written notice if a change is proposed in their child's classification, evaluation, or educational placement.
- Parents have a right to an impartial due process hearing conducted by a hearing officer, and/or mediation if they are in disagreement with the school district. Parents have the right to be represented by a lawyer, to give evidence, and to cross-examine. Hearings may be requested by the parent or by the school district.
- Surrogate parents must be appointed to provide representation and informed consent for children whose parents or guardians are not known, or who are not available.

Chronology of Laws and Key Components

1975 The Education for All Handicapped Children Act (P.L. 94-142)

Part B of The Education for All Handicapped Children Act requires: that states furnish all children with disabilities (ages 6 to 21) a free, appropriate public education in the least restrictive environment; the provision of special education and related services designed to meet the unique needs of these children; and the development of an Individualized Educational Plan for each child.

1986 Amendments to The Education for All Handicapped Children Act (P.L. 99-457)

The addition of Part H requires: the development of "a statewide, comprehensive, coordinated, multidisciplinary, interagency system to provide early intervention services for infants and toddlers (birth to three years of age) with disabilities and their families"; the establishment of a State Interagency Coordinating Council; and the development of an Individualized Family Service Plan for each eligible infant or toddler and his or her family. Part B is expanded to include special education preschool services for children from ages 3 to 5.

1990 The Americans with Disabilities Act (ADA)

ADA is a wide-ranging civil rights law that prohibits discrimination against people with disabilities or physical and mental impairments that substantially limit their activities such as working, walking, talking, seeing, hearing, or caring for themselves. ADA requires that employers make reasonable accommodations for employees with disabilities and the prohibition of discrimination in commercial facilities and in any activity or service operated or funded by state or local government, including daycare centers and other programs which serve children ***without*** disabilities.

1991 Individuals with Disabilities Education Act (P.L. 101-476, IDEA)

The change from the "Education for All Handicapped Children" to the "Individuals with Disabilities Education Act" reflects shifts the terminology from "**handicaps**" to "**disabilities**", use of people first language (a person *with* a disability, a child *with* cerebral palsy), and encompasses all of the components from The Education for All Handicapped Children Act and its amendments.

1994 Families of Children with Disabilities Support Act (sec. 315 of P.L. 103-230)

Under this act all programs, projects, and activities receiving federal funds from IDEA must demonstrate the practices of family centered care. The law provides nine principles that ensure family centered and family directed programming.

Part A-General Provisions

Special Education

Special education is defined as "specially designed instruction, delivered at no cost to the parent, to address the unique needs of the child" in accordance with an Individualized Education Plan (IEP). The child may receive this instruction in the classroom, in the home, in hospitals, and in other settings, such as community early childhood programs.

Eligible Disabilities

Under Part A, general provisions, eligible disabilities include:

- Mental retardation
- Hearing impairments
- Speech and language impairments
- Visual impairments, including blindness
- Serious emotional disturbance
- Orthopedic impairments
- Autism
- Traumatic brain injury
- Other health impairments
- Specific learning disabilities

Related Services

These include transportation and other developmental, corrective, and supportive services as required to assist a child with a disability to benefit from special education. They include:

- Speech therapy

- Audiology
- Psychological services
- Physical and occupational therapy
- Recreation, including therapeutic recreation
- Early identification and assessment of disabilities in children
- Counseling services, including rehabilitative counseling
- Medical services for diagnostic or evaluative purposes
- School health services (e.g., tube feeding, suctioning, catheterization, etc.)
- Social work services in schools
- Parent counseling and training

Transition Services

These are designed for secondary-age students. They include a coordinated set of activities that promotes movement from school to post-school living, including post-secondary education, vocational training, integrated employment, supported employment, continuing adult education, adult services, independent living, and community participation. These long term, outcome oriented activities are based on the individual student's needs, preferences, and interests and are incorporated into the student's **Individual Transition Plan** no later than his or her ***16th birthday***. A statement of interagency roles, responsibilities, and linkages must also be incorporated. The local education authority is responsible for initiating transition planning for students with disabilities with the cooperation of representatives from adult services agencies.

Part H-Early Intervention Services for Infants and Toddlers

Under Part H of IDEA, early intervention services for infants and toddlers (ages birth to three) must be provided within a statewide, comprehensive, coordinated, multidisciplinary, and interagency model of service delivery. The components of this service delivery model are described below.

Lead Agency

Each state is to designate a lead agency that will be responsible for the administration of funds under Part H. In Connecticut, the lead agency has recently shifted from the **State Department of Education** to the **Department of Mental Retardation.**

State Interagency Coordinating Council

Each state is required to establish a State Interagency Coordinating Council (ICC) whose role is to advise and assist the early intervention lead. Members of the state ICC are appointed by the Governor, in accordance with the following federal guidelines:

- At least 20% of the membership must be parents of children with disabilities, birth through age twelve.
- At least one representative from the state legislature.
- At least 20% of the membership must be providers, both public and private, of early intervention services.
- At least one person representing the training of personnel.
- At least one representative of the state governance of insurance.
- Other members representing the state agencies involved in early intervention services for infants and toddlers with

disabilities and their families (Education, Mental Retardation, Children and Families, Health and Addiction Services, Social Services, Office of Protection and Advocacy, Board of Education and Services for the Blind, and Commission on the Deaf and Hearing Impaired.).

Point of Entry

The **Comprehensive Child Find** system is established as the point of entry into the early intervention system. This system must include procedures to ensure that all eligible infants and toddlers are identified, located, and evaluated. Connecticut has a single point of entry through **INFOLINE**, a statewide service that provides referral to Birth to Three services, as well as information of other community based services for children and families.

Individualized Family Service Plan (IFSP)

Each eligible infant or toddler and his or her family shall receive a multidisciplinary assessment and, based on information from these evaluations, an Individualized Family Service Plan (IFSP) will be developed.

Service Coordination

A service coordinator is appointed and is responsible for assisting an eligible child and his or her family to receive the rights, procedural safeguards, and services that are provided under the early intervention program. Service coordinators serve as the single point of contact for the family and all service providers. Service coordination is provided at no cost to the parents.

Payment

As Part H does not come under a free, appropriate education, the lead agency will establish "policies related to how services to children eligible under this part and their families will be paid for." In addition, "the inability of the parents of an eligible child to pay for services will not result in the denial of services to the child or the child's family." (P.L. 101-476, Section 303.520). Thus, early intervention services are provided ***at no cost*** to families.

Types of Services Available under Part H

Assistive technology device: using any item, piece of equipment, or product system to increase, maintain, or improve the functional capabilities of a child with disabilities. Examples include a switch controlled toy, picture communication board, or a feeding chair.

Assistive technology services: directly assisting in the selection, acquisition, or use of an assistive technology device. Examples include fittings for a specific devise, maintenance, and ongoing training and support.

Audiology: identifying children with auditory impairments; referral for medical and other necessary services; provision of auditory training; determination of the child's need for individual amplification.

Family training, counseling, and home visits: providing services of social workers, psychologists, and other qualified personnel to assist the family of a child in understanding the special needs of the child and enhancing the child's development.

Health services: enabling a child to benefit from other early intervention services, including such services as clean intermittent catheterization; tracheostomy care; tube feeding; changing of dressings or colostomy collection bags; other health services; and consultation by physicians with other service providers concerning the special healthcare needs of children that must be

addressed in the course of providing other early intervention services.

- ***Medical services only for diagnostic or evaluative purposes:*** diagnosing and evaluating to determine a child's developmental status and need for early intervention services. These services must be provided by a licensed physician.

Nursing services: assessing a child's health status; providing nursing care; provision of nursing care to prevent health problems, restore or improve functioning, and promote optimal health and development; administration of medications, treatments, and regimens prescribed by a licensed physician.

Nutrition services: conducting individual assessments; developing and monitoring plans to address the nutritional needs of children; making referrals to community resources to carry out nutrition goals.

Occupational therapy: addressing the functional needs of a child related to adaptive development, adaptive behavior and play, and sensory, motor, and postural development designed to improve the child's functional ability to perform tasks in home, school, and community settings.

Physical therapy: promoting sensorimotor function through the enhancement of musculoskeletal status, neurobehavioral organization, perceptual and motor development, cardiopulmonary status, and effective environmental adaptation.

Psychological services: administering psychological and developmental tests and other assessment procedures; interpreting assessment results; obtaining, integrating, and interpreting information about the child's behavior, and the child and family conditions with regard to learning, mental health, and development; planning and managing a program of psychological services.

Service coordination: coordinating all services across agency lines; serving as the single point of contact; assisting parents in gaining access to early intervention services and other services identified in the Individualized Family

Service Plan; coordinating the provision of early intervention services and other services (such as medical services for other than diagnostic and evaluation purposes) as needed.

Social work services: evaluating the child's living conditions and patterns of parent-child interaction; preparing a social or emotional developmental assessment of the child within the family context; providing counseling to parents, other family members, and the child and parents together; identifying, mobilizing, and coordinating community resources and services to enable the child and family to receive maximum benefit from early intervention services.

Special instructional services: designing learning environments and activities that promote the child's acquisition of skills in a variety of developmental areas, including cognitive processes and social interaction; planning a curriculum that will achieve the outcomes in the child's Individualized Family Service Plan; providing families with information, skills, and support related to enhancing the skill development of their child; working directly with the child to enhance development.

Speech/language pathology: identifying children with communicative or oropharyngeal disorders, or delays in the development of communication skills; referral for medical or other professional services; provision of direct services.

Transportation and related costs: covering the cost of travel (e.g., mileage, or travel by taxi, common carrier, or other means) and other costs (e.g., tolls and parking expenses) necessary for the child and the child's family to receive early intervention services.

Vision services: evaluating and assessing visual functioning, including the diagnosis and appraisal of specific visual disorders, delays, and abilities; referral for medical or other professional services; communication skills training; orientation and mobility training in all environments; visual training; additional training necessary to activate visual motor abilities.

A Self-Check for Understanding IDEA

- ❑ Do I understand the five basic components of IDEA?
- ❑ Am I aware of the eligible disabilities and related services available to children ages 3-21 under the general provisions of IDEA?
- ❑ Do I know the Lead Agency for administration of funds for early intervention services in Connecticut?
- ❑ Have I had contact with individuals who serve on the Local Interagency Coordinating Council for the community in which I practice?
- ❑ Do I know how the Comprehensive Child Find system is set up in Connecticut, and how to contact the point of entry for early intervention services?
- ❑ Am I aware of the components of the Individualized Family Service Plan?
- ❑ Do I understand the role of the service coordinator in early intervention, and do I know who the service coordinator is for children with disabilities in my practice?
- ❑ Am I aware of the types of services available to children ages birth to three?
- ❑ How do I provide family members with information about IDEA, as well as other laws that serve children?

TIPS

Family Centered Healthcare

Family centered care is both a philosophy and a set of practices originally developed by the former Surgeon General, C. Everett Koop, M.D., Sc.D. As a philosophy it encompasses the key premises of "best practices" in healthcare and in early intervention programming. Best practice requires the provision of services that are comprehensive, collaborative, coordinated, family centered, culturally competent, and community based. In 1994, the **Families of Children with Disabilities Support Act** was passed. The language of this law is landmark in its approach to family support. While passed unfunded, the intent is to provide financial incentives to states that develop comprehensive family support systems. The law established a comprehensive, coordinated system of family support that avoids duplication of services, makes efficient use of existing resources, and prevents gaps in services to families of children with disabilities. The primary goal of Act was the establishment of a state **Family Support Council**, the composition of which is 66% parents. The Lead Agency of the Connecticut Family Support Council is the Department of Mental Retardation. The Family Support Council is charged with overseeing the implementation of state programs that:

Families are and should be the center of service delivery systems designed to meet their needs and those of their children.

- Strengthen the family and maintain family unity.
- Enable all children with disabilities the opportunity to grow up within their family.
- Enable children and families to find the support services they need to have typical lives in the community.
- Reduce the costs to families who care for children with disabilities at home.
- Provide a quality of life comparable to that of similarly situated families who do not have a child with a disability.

- Enhance the capacities of all family members.

The major premise of the family centered approach in healthcare ***and*** early intervention is that the child is a member of a family, and that family is the ***center of care*** that provides for the child's development and well-being. Family centered care supports family members in their natural care giving roles, promotes typical patterns of living, and ensures that family members have choices in the provision of services to their child. To practice in a family centered manner, it is important to build relationships based on mutual trust and respect.

Principles of Family Centered Care

The original philosophy of family centered care has been expanded to incorporate nine principles that provide guidance for developing systems of care ***and*** service delivery models for children with disabilities and special healthcare needs, while also supporting the needs of families. The nine principles include:

① ***Recognizing that the family is the constant in the child's life, while the service systems and personnel within those systems fluctuate.***

Children with disabilities and special healthcare needs move through multiple service delivery systems and are involved with many different healthcare professionals, service providers, and specialists. However, throughout the child's life family members play the central and consistent role in their child's life. Since family members are the constant, it is essential to value their judgment, observations, beliefs, and hopes.

② ***Facilitating family-professional collaboration at all levels of healthcare.***

Healthcare plans should be developed collaboratively with families, physicians, and other healthcare and service providers. The healthcare plan needs to reflect the family's strengths and be tailored to meet the family's needs as defined by the individual members. Skills for

alliance building and collaboration are essential to this process.

③ ***Honoring the racial, ethnic, cultural, and socioeconomic diversity of families.***

Each family has its own beliefs, values, strengths, and needs. To be culturally competent, it is necessary to not prejudge a family or impose one's own values or cultural expectations on the family.

④ ***Recognizing family strengths and individuality, and respecting different methods of coping.***

Each family defines itself differently and has its own strengths and sources of support, which professionals can help to identify. Families nurture and respond to children's needs differently and ***all parents*** wish to feel competent in caring for their children. There must be recognition and respect for the uniqueness and strengths of each family system and each of its members.

⑤ ***Sharing with parents, on a continuing basis and in a supportive manner, complete and unbiased information.***

Parents need to have access to information about their child. This information should be shared in language that is clear and understandable, including diagnosis, prognosis, treatment options, and available resources. With complete information, parents are better able to make informed decisions about the care of their child and to participate as equal partners in providing that care.

⑥ ***Encouraging and facilitating parent-to-parent support and networking.***

Support from other families with similar experiences can be extremely valuable. Through parent-to-parent contact, family members can develop a network of resources and information, enhance their practical skills for providing care to their child, and gain emotional support from others who may truly understand.

⑦ ***Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into healthcare delivery systems.***

A comprehensive healthcare plan should incorporate the medical, developmental, and social needs of the child, and the needs of family members in caring for their child. The healthcare plan should encourage each child and family to have as normal a life as possible.

⑧ ***Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families.***

Family support protocol suggests that families have access to ***"whatever it takes"*** to enable them to maintain their integrity as a family, and their goals and visions. The family's needs may include financial support, respite, child care, service coordination, parent-to-parent support, transportation, adaptive equipment, assistive technology, housing modifications, and advocacy. Professionals can play a vital role in linking families to these resources.

⑨ ***Designing accessible healthcare systems that are flexible, culturally competent, and responsive to family identified needs.***

Inflexible or fragmented service delivery systems are often a greater source of stress for families than the daily care of their children. Healthcare and service providers need to attend to the ever-changing needs of each child and family with a flexible, accessible, and responsive system of services.

A Self-Check for Family Centered Healthcare

The Family as Constant

- ❑ How do I help family members identify their needs, concerns, and priorities?
- ❑ How can I be more consistent in seeking family members' input and observations about what works and what does not work in caring for their child?
- ❑ How can I ensure that my recommendations take into account the family's needs and concerns?

Collaboration

- ❑ In what ways can I encourage parental participation in all phases of the child's care and in the decision making process?
- ❑ How can I effectively and efficiently communicate with other healthcare professionals and service providers who provide services to this family?
- ❑ How can I become more available for consultation with other healthcare professionals and service providers?

Honoring Diversity

- ❑ How can I become more attuned to the family's cultural values and belief systems, particularly when making recommendations for treatment and intervention?

Strengths and Individuality

- ❑ What strategies can I use to help family members identify their own strengths?
- ❑ What strategies can I use to help family members identify their own sources of support, both formal and informal?
- ❑ How can I become more aware of the strengths and needs of the family as a whole, and each of its individual members?

Sharing Information

- ❑ In what ways can I become better at providing family members complete information about their child in terms of diagnosis? Prognosis? Treatment options? Available resources?
- ❑ How can I ensure that the information I present is clear and understandable? Is it presented in the family's primary language?
- ❑ How can I more fully support parents' decision making skills, and respect their decisions?

Support Networks

- ❑ In what ways can I encourage the family to seek support from other families and appropriate agencies?
- ❑ In what ways can I best provide families with information about other sources of support?

Developmental Needs

- ❑ How can I ensure that my recommendations for treatment allow parents to attend to the "typical"

developmental needs of their child and to the "typical" needs of family life?

Policies and Programs

- ❑ Do I inform families of agencies, programs, and services that can assist them in dealing with all of the concerns related to the care of their child?

Healthcare

- ❑ How can I be proactive and respond in a timely manner to the changing needs of each child and family?
- ❑ How can I ensure that my services accessible and flexible to meet these changing needs?
- ❑ What more can I do to ensure that the services I provide are in keeping with the principles of Family Centered Care?

TIPS

Cultural Competence

Diversity exists in many forms: race, gender, age, language, physical characteristics, disability, sexual orientation, economic status, parent/family status, education, geographic origin, profession, life style, religion, and any other conceivable difference. Best practices in pediatric care and early intervention call for open, supportive, and responsive environments in which differences are valued and encouraged. If an open environment is to be created, everyone involved needs to be aware of his or her attitudes, beliefs, and actions and how these may impede or enhance work with those who are viewed as different.

Cultural competence requires a move from ignorance, prejudice, discrimination, and stereotyping toward an awareness and respect for diversity. A desire to expand one's knowledge of cultural differences and how these impact interactions with children, families, and colleagues is essential. Cultural competence refers to specific skills that help translate beliefs, attitudes, and orientation into actions and behaviors in daily interactions with children, families, and colleagues. It is the capacity to recognize and respond to the needs of those who are different from oneself.

> **"Every person is, in many respects, like all other people, like some other people, like no other person."**
>
> **C. Kluckhohn & H. A. Murray (1948)**

The term ***cultural*** is used to describe patterns of behavior, communication, customs, beliefs, values, and institutions of a specific racial, ethnic, religious, or social group. In actuality, cultural differences exist even between different professional groups and between the "culture of" the medical profession and the "culture of" the family. In parent-physician alliances each of member needs to understand the differences that the other brings to the task of providing care to a child with disabilities or special healthcare needs. Parents, and healthcare and service providers all bring unique beliefs, concerns, priorities, and responsibilities to the situation. These can be viewed as ***cultural differences,*** and require attention in the same manner as other more commonly thought of

cultural differences. In forming equal partnerships, these differences need to be honored and respected.

Cultural competence builds upon the principles and practices of family centered care. Understanding the family within their cultural context is an essential factor in providing care to the child and ultimately to the entire family. The cultural context as defined by the family is often the primary support network for that family. The following set of principles and values will provide guidance in assuring that culturally competent healthcare is being given to all children and their families.

Respect for difference and diversity

Professionals need to increase their awareness of and respect for difference, value diversity, and view diversity as an asset to care practices. Cultural patterns determine behavior and choices that families make regarding the care of their children. Exploring and gaining knowledge of the family's culture, and its differences in beliefs, practices, interpersonal and communication styles, and life view is necessary for developing cultural competence. Individuals have their own definitions of health and family, and their thought patterns and behaviors are based on these perspectives. In understanding the cultural context and preferences of families, one can more capably support their ability to recognize problems, make choices, and take responsibility for creating solutions.

The capacity for cultural self-assessment

What professionals bring to their interactions with others is impacted by personal experiences and cultural backgrounds. Thus, an awareness of one's own cultural beliefs and behaviors and how they influence interactions with others is essential.

The dynamics of difference

There are dynamics that occur when people from different cultures interact. Professionals need to be aware of how this affects the helping process. Difference can create discomfort or conflict. There may be misunderstandings, a history of distrust, or errors in judgment and expectations between individuals from different cultural backgrounds. One needs to address these dynamics openly and with sensitivity.

Flexible service models

Services and service models need to be adapted to meet the needs of diverse populations. This flexibility needs to be incorporated into office practices and policies. Service provision needs to fit the family's cultural context, and to be truly accessible, acceptable, and available. It is important to develop help-giving practices that are culturally supportive and enriching, and that allow families to feel comfortable in medical settings.

Culturally appropriate resources

Families must be linked with natural informal support systems and helping networks within the community. Natural support systems include the extended family, the neighborhood and community, spiritual and religious groups and leaders, places of worship, schools or daycare programs, etc.

"The absence of cultural competence anywhere is a threat to competent services everywhere."

T. L. Cross, et. al. (1989)

A Self-Check for Cultural Competence

- ❑ What can I do to show respect for the individuality of each person and family with whom I work?
- ❑ How can I more effectively demonstrate a respect for diversity and an acceptance and appreciation of differences?
- ❑ How can I become more open to learning about the culture and beliefs of families, particularly related to the care of their children?
- ❑ How can I become more attentive to the "cultural differences" that exist between being a healthcare provider and being a parent?
- ❑ How can I become more aware of how my cultural background effects my perceptions, behaviors, and choices both in my life and in my work?
- ❑ How can I demonstrate that I am willing to consider differences in viewpoint?
- ❑ What strategies can I use to discuss disagreements openly with family members?
- ❑ How can I more fully support parents as they define problems and make decisions within their own cultural context?
- ❑ How can I ensure that the services provided through my practice are flexible enough to meet each family's needs?
- ❑ In what ways can I help family members find natural sources of support within the community?
- ❑ What more can I do to ensure that my office functions in a culturally competent manner?

TIPS

Care Coordination and The Medical Home

Changes in the field of providing care to children with disabilities and special healthcare needs require the incorporation of social systems and family systems perspectives in addition to clinical perspectives. Best practices in primary care show that family centered, comprehensive, coordinated, and community based services are most effective in meeting the needs of children and their families. Families need to be recognized as the primary caregivers and advocates for their children, and to be supported in these roles. An expanding set of responsibilities and skills are now required of physicians and other healthcare providers.

"To be fully effective, health supervision must be part of a seamless system, integrated with other health and human services such as secondary and tertiary care..., child care centers, early intervention programs, mental health centers, diagnostic and evaluation programs, schools, family support centers...."

M. Green (1994)

Key Aspects of the Physician's Role

Identification

Identifying disabilities, developmental delays, high risk situations, and special healthcare needs; and providing developmental evaluations, screening, surveillance, and assessment.

Referral

Referring children with delays, disabilities, or special healthcare needs to early intervention services, the special education system, and other agencies or sources of support, both medical and nonmedical.

Support

Helping family members identify their own concerns, priorities, and resources; providing regular and accessible communication to families; and connecting families with community resources and informal support systems.

Collaboration

Participating in the process of developing and implementing the Individualized Family Service Plan (IFSP) or Individual Education Plan (IEP); and providing consultation with the service coordinator or case manager and other service providers.

Coordination

Providing coordination for all the child's healthcare needs; assuring continuity of care; and communicating with other healthcare providers.

Partnering

Viewing families as partners in the care of their children and in their ability to act as advisors to the medical practice.

"If such medical and healthcare services truly are to prepare the child to participate optimally in the continuum of other early intervention services, an inherent component of the process must include involvement of the pediatrician and the child's medical home in the planning, implementation, and monitoring of the healthcare and medical components of the child's IFSP."

American Academy of Pediatrics (1995)

F. Gallagher and C. Garland (1994) outline an extensive set of competencies for physicians and healthcare providers who provide care to infants and toddlers with disabilities. These competencies reflect the practices above and include specific objectives for identifying children, assessing abilities and disabilities, developing and implementing Individual Family Service Plans, and for transitioning children from early intervention services to the public school system.

Obstacles to Referring Children for Services

Physicians and other healthcare and service providers may be reluctant to suggest that parents seek early intervention services for their child. This may avert or delay the identification or diagnosis of developmental difficulties or at risk situations for children No one wants to unnecessarily alarm parents. However, delays or reluctance on the part of the healthcare provider may increase parental anxiety and cause the child to miss essential early intervention opportunities. Obstacles to making referrals may include:

- Needing more knowledge, awareness, or experience in terms of specific delays or disabilities.
- Being concerned about the parent's emotional reactions to the "bad news" or assuming that the parents are "not ready" to hear the information.
- Not acknowledging what parents communicate in terms of their concerns, observations, and hunches.
- Wanting to use a "wait and see" approach.
- Not wanting to unnecessarily alarm the parents with a hasty or premature diagnosis.
- Not having sufficient information to make a confirmed diagnosis.
- Being concerned about the uncertainty of prognosis.
- Wanting to assume total responsibility for the child's care without collaboration with other healthcare professionals and service providers.
- Feeling uncomfortable with the fact that there may be no successful treatment or cure, or no restoration to "normal functioning".

It is important that physicians and other healthcare providers not permit these concerns to interfere with referrals to the large number of services available for children with disabilities and special healthcare needs and the families that care for them.

The Medical Home

Establishing a "medical home[1] " for children is in keeping with best practices in pediatric healthcare ***and*** early intervention. The medical home model helps physicians and other healthcare providers deliver care to children that is family centered, community based, comprehensive, and coordinated. Opportunities are enhanced for effective collaboration between physicians, other healthcare providers, and the community agencies involved in providing services to children with disabilities and special healthcare needs and their families.

"A medical home supports the family, recognizes the importance of continuity, and builds upon an enduring relationship that spans a childhood."

American Academy of Pediatrics (1995)

The American Academy of Pediatrics supports the medical home concept where comprehensive, coordinated, and family centered healthcare can be provided to all infants, children, adolescents, and young adults, particularly those with disabilities or special healthcare needs. In an addendum to the Medical Home Statement, the American Academy of Pediatrics provides a definition of Pediatric Primary Healthcare, which encompasses provision of first contact care; diagnosis and treatment of acute and chronic disorders; management of serious and life-threatening illness; and coordinated management of health problems requiring multiple professional services.

[1]The Medical Home Program (RE9262): Ad Hoc Task Force on Definition of The Medical Home. For more information, contact Marcia Di Verde, AAP Department of Community Pediatrics, (800) 433-9016, ext. 7621.

Services within the Medical Home Program

- Provision of preventive care including, but not restricted to, immunizations, growth and development assessments, appropriate screening, healthcare supervision, anticipatory guidance, and patient and parental counseling about health and psychosocial issues (anticipatory guidance).
- Assurance of ambulatory and inpatient care for acute illnesses, twenty-four hours a day, seven days a week, during the working day, after hours, on weekends, fifty-two weeks a year.
- Provision of care over an extended period of time to enhance continuity.
- Identification of the need for subspecialty consultation and referrals, and knowing from whom and where these can be obtained; provision of medical information about the patient to the consultant; evaluation of the consultant's recommendations, implementation of recommendations that are indicated and appropriate, and interpretation of these to the family.
- Interaction with school and community agencies to be certain that the special health needs of the individual child are addressed.
- Maintenance of central record and data base containing all pertinent medical information about the child, including information about hospitalizations. This record should be accessible, while maintaining confidentiality.

The Medical Home Program for Children with Special Needs also provides support to physicians to enhance their healthcare practices for children with disabilities or special healthcare needs. This program provides information about strategies and educational materials, as well as technical assistance to physicians, for developing a medical home program within their practice.

Coordinating Services

Often there are overwhelming numbers of healthcare and service providers involved in the care of children with complex needs. Each person's role and responsibilities need to be clearly defined. Parents must be asked what their expectations are for each of the healthcare and service providers. This will reduce the confusion parents might have as to which provider to turn to when they have a specific need. Thus, their needs will be more efficiently and effectively met. In addition, there must be clearly stated guidelines among all involved in the collaborative process.

Who Collaborates

- Parents
- Other family members
- Physicians
- Other healthcare providers
- Medical specialists
- Service providers
- Service coordinators
- Case managers
- Daycare personnel
- School personnel
- Anyone else involved in a child's care

A Self-Check for Care Coordination

- ❑ How can I enhance my system for communicating with other healthcare personnel, specialists,. and other service providers (via phone, letter, or the parents)?
- ❑ Do I know who the **care coordinator** or primary contact person is for the child's medical care? Does the child have a medical home?
- ❑ Do I know who the **service coordinator** is for children enrolled in an early intervention program?
- ❑ Do I know where to find complete medical records for a child?
- ❑ How can I enhance my communication with other healthcare and service providers routinely, under special circumstances, or when there are changes in condition and treatment?
- ❑ Am I made aware of team or IFSP meetings? How can I participate in these meetings? By phone? By letter?
- ❑ How can I ensure that other service providers, early interventionists, teachers, or the school nurse have appropriate and up to date information on the child's healthcare needs?
- ❑ Do I know who is providing preventive, routine, sick and well healthcare services for each child? Who attends to the acute or specialty care needs of the child?
- ❑ Am I certain about who is implementing and monitoring the various medical interventions for children who are involved with several healthcare providers?
- ❑ Do I feel that it is appropriate to ask parents to be responsible for sharing information between healthcare providers? If not, what system do I have in place to accommodate this need?

- ❑ How can I ensure parents know which healthcare provider to contact for a specific need that arises?

TIPS

Communicating with Families

For families of children with disabilities or special healthcare needs the issues, tasks, and goals of caring for their child can be extremely complex and overwhelming. Effective communication processes are essential when families, physicians, and other healthcare and service providers work together, to create successful outcomes for all involved, and particularly for the child. It is not only the ***exchange*** of information that is important for communication, but the ***process*** by which information is exchanged. Listening, questioning, and responding are basic communication skills that facilitate understanding, a supportive climate, and trust between healthcare providers and families. In turn, trustworthiness reduces the risk of communicating openly and allows everyone to work towards commonly shared goals in the care of children.

Communication that Benefits Families

Family members will often communicate important information about their life style, family values, needs, feelings, strengths, and coping strategies. They will talk about people who are supportive, what they would like to do to help their child, and concerns they need to have addressed. Professionals need to attend to what family members communicate, using effective communication skills such as:

- ***Responsive Listening***: An active task that requires intention, energy, and constant attempts to ensure understanding. Family members will feel they are understood when we use ***verbal cues*** to paraphrase, summarize, and reflect on the feelings and information that they have conveyed. Subtle ***nonverbal cues*** also help family members to feel that what they are communicating is important. Leaning forward, maintaining eye contact, nodding, taking notes, and using vocalizations are nonverbal cues that encourage communication.

- ***Empathic Listening:*** Understanding feelings that accompany the thoughts a parent is communicating. When professionals attend to the feelings of family members, understanding, support, and trust are enhanced.

- ***Interactive Questioning:*** Seeking, clarifying, and confirming information to enhance understanding. Family members benefit when questions are specific, concrete, and focused, asked one at a time, and in ways that make them easy to answer.

- ***Responding:*** Providing comments to parents that reflect impressions, feelings, and observations. Feedback is helpful to family members when it is descriptive of reactions, rather than judgmental of their behaviors. ***Open ended*** responses show understanding, acknowledgment, support, and interest. These responses lead to continued communication and enhanced trust. ***Closed ended*** or vague and ambiguous responses tend to block communication and lead family members to feel discouraged or defensive.

- ***Dialogue:*** Combines the skills of responsive and empathic listening, interactive questioning, and responding. Dialogue ensures understanding of each others' concerns and priorities. It encourages family members to develop their own thoughts, ideas, and possibilities. Effective dialogue creates a united process, and enhances the ability to be open-ended and creative in solving problems and meeting the needs of children with disabilities and special healthcare needs.

Concerns, Priorities, and Resources

The principles of family centered care recognize that the family is at the center of the child's care and is the constant in providing that care. The skills of responsive and empathic listening, interactive questioning, responding, and dialoguing are particularly relevant for working with family members to help them define their concerns, priorities, and resources for the care of their child. Early intervention philosophy suggests that physicians, healthcare providers, and service providers can be vital in helping family members identify and meet their needs and those of their child with disabilities or special healthcare needs.

Family Needs

- Economic
- Physical & Environmental
- Food & Clothing
- Medical & Dental
- Transportation & Communication
- Vocational & Employment
- Adult Education & Enrichment
- Child Education & Intervention
- Child Care
- Recreational
- Emotional
- Cultural & Social

- ***Family Concerns***: Needs, issues, or problems that the family identifies and seeks assistance in addressing.

- ***Family Priorities***: A family's preferences and choices for which services will be provided and how these services are implemented.

- ***Family Resources***: The strengths and abilities of family members, as well as the formal and informal support systems that can be utilized to meet the family's stated concerns and priorities.

When helping families define their concerns, priorities, and resources, one needs to remember that ***family members*** determine which concerns, priorities, and resources are relevant to their life style, life view, and their child's development.

Carl J. Dunst and colleagues (1988) developed a taxonomy of "need categories" that can be used to help families identify their needs. They also developed The Family Needs Scale and The Family Support Scale, valuable tools for identifying a family's needs and resources or support networks. (See pages 40-41).

Conveying Difficult Information

Sharing diagnostic information with parents about their child can be difficult and complex for physicians and other healthcare providers, as well as for the parents. Having a child with disabilities or special healthcare needs can impact the family and its functioning in different ways. It is important to consider how each family can be affected in these areas:

- Family dynamics, interactional patterns, and decision making.
- Family planning and participation in the community.
- Finances and employment.
- The spousal relationship, sibling relationships, and relationships with extended family members and friends.
- Roles and responsibilities in caring for the child.

It is a family's right to have complete information about the child's illness or disability. How that information is conveyed will make a difference in how parents understand and cope with what they are told. With complete information, parents can make informed decisions about the care of their child. Additionally, the alliance with family members is strengthened, and parents can actively participate as partners in caring for their child.

The issue is not *whether* to share information, but *how* to share information

Presenting information in an organized manner, and providing family members opportunity for discussion and questions is helpful in ensuring their understanding. Following are some guidelines for conveying difficult information to families.

Family history session

The family history session is a time to explore parents' ideas about the problem, etiology of the symptoms, insights, observations, and expectations. It should be acknowledged that parents have a great deal of expertise about their child. Parents need to understand that history taking is necessary to gain a better sense of their concerns and questions, and that they are not being judged or blamed.

Presentation of findings

When presenting information about the child, a dialogue must be created among family members and team members. Rather than a one-way presentation, effective communication skills can be used to ensure that parents understand what is discussed and ask questions when clarification is needed. During the presentation of findings or information about the child, the following suggestions will help parents feel more comfortable and be more receptive:

- Strongly encourage parents to bring others who will be supportive of them.
- Review parents' observations and concerns.
- Discuss concerns for the child in clear, understandable language. Connect the parents' observations and concerns to clinical understanding. Diagnostic and clinical terminology can be presented later.
- Link observable manifestations to internal processes and provide reasons for what parents observe.

Diagnosis and clinical findings

At this point parents need to hear the diagnostic and clinical terminology, as ***not*** using it may leave them fearful and uncertain.

- Explain the terminology in understandable, clear, and concise language.
- Provide information that is specific, complete, and accurate.
- Discuss diagnosis, prognosis, treatment options, and recommendations. Parents need to feel that they have choices about the treatment for their child.
- Ask parents whether the information makes sense to them or whether they need clarification or additional explanation.
- Provide parents the opportunity to ask questions. Recognize that they may be overwhelmed at this point, and may not have questions until later. Assure them that you will be available to address their questions at a later time.
- Discuss referrals to early intervention and additional healthcare services.
- Provide information about parent support networks, organizations, and advocates. Ask if they would like another parent to contact them, as they may not reach out for support.
- Have printed resource materials about the child's diagnosis available.
- Immediately provide a written report that summarizes the discussion, the clinical findings, diagnosis, and recommendations.
- Identify and explain the levels of care the child will need and the responsibilities of all care providers.

Family Member Reactions

Each family and each individual in that family will react differently to learning that one of its members has a disability or healthcare need. A wide range of emotions and behavioral responses are possible and professionals need to find ways to be sensitive to, not critical of these responses.

It is important to let family members know that their feelings are acceptable and that they may experience many feelings at the same time. They need to know that their feelings are understandable, adaptive, and normal responses to a significant life change. Parents need support to explore their fears, worries, confusion, questions, and other emotional responses. Parents may need help to identify their needs for additional emotional support. When parents explore their feelings in a supportive environment, their ability to move toward active parenting and to make decisions about treatment is enhanced. When parents are perceived to be "non-compliant", it is the professional's responsibility to assess whether they have been helped to identify and express ***their*** needs, and whether those needs have been addressed. ***All parents*** want to feel competent. When their self-identified needs are met, they can fully participate in caring for their child.

Providing Support to Parents

- Be available and approachable.
- Assure parents that you will do whatever it takes to respect and preserve the integrity of their family life.
- Respect parents' need to have hopes, dreams, and expectations for their child.
- Acknowledge parents' competencies and ability to do what they believe is best for their child.
- Convey a belief that every child has potential and will develop.
- Support normal living patterns in the home and community with treatment that is least disruptive to the child and family.
- Offer suggestions for resources and support within the community.
- Allow yourself to say ***"I don't know, I'm not sure, I'll find out".***

BEST COPY AVAILABLE

Family Needs Scale [1]

Name _____ Date _____

This scale asks you to indicate if you have a need for any the of help or assistance in 41 different areas. Please circle the response that best describes how you feel about needing help in those areas.

To what extent do you feel the need for any of the following types of help or assistance:	Not Applicable	Almost Never	Seldom	Sometimes	Often	Almost Always
1. Having money to buy necessities and pay bills	NA	1	2	3	4	5
2. Budgeting money	NA	1	2	3	4	5
3. Paying for special needs of my child	NA	1	2	3	4	5
4. Saving money for the future	NA	1	2	3	4	5
5. Having clean water to drink	NA	1	2	3	4	5
6. Having food for two meals for my family	NA	1	2	3	4	5
7. Having time to cook healthy meals for my family	NA	1	2	3	4	5
8. Feeding my child	NA	1	2	3	4	5
9. Getting a place to live	NA	1	2	3	4	5
10. Having plumbing, light, heat	NA	1	2	3	4	5
11. Getting furniture, clothes, toys	NA	1	2	3	4	5
12. Completing chores, repairs, home improvements	NA	1	2	3	4	5
13. Adapting my house for my child	NA	1	2	3	4	5
14. Getting a job	NA	1	2	3	4	5
15. Having a satisfying job	NA	1	2	3	4	5
16. Planning for future job of my child	NA	1	2	3	4	5
17. Getting where I need to go	NA	1	2	3	4	5
18. Getting in touch with people I need to talk to	NA	1	2	3	4	5
19. Transporting my child	NA	1	2	3	4	5
20. Having special travel equipment for my child	NA	1	2	3	4	5
21. Finding someone to talk to about my child	NA	1	2	3	4	5
22. Having someone to talk to	NA	1	2	3	4	5
23. Having medical and dental care for my family	NA	1	2	3	4	5
24. Having time to take care of myself	NA	1	2	3	4	5
25. Having emergency health care		NA	1	2	3	4
5						
26. Finding special dental and medical care for my child	NA	1	2	3	4	5
27. Planning for future health needs	NA	1	2	3	4	5
28. Managing the daily needs of my child at home	NA	1	2	3	4	5
29. Caring for my child during work hours	NA	1	2	3	4	5
30. Having emergency child care	NA	1	2	3	4	5
31. Getting respite care for my child	NA	1	2	3	4	5
32. Finding care for my child in the future	NA	1	2	3	4	5
33. Finding a school placement for my child	NA	1	2	3	4	5
34. Getting equipment or therapy for my child	NA	1	2	3	4	5
35. Having time to take my child to appointments	NA	1	2	3	4	5
36. Exploring future educational options for my child	NA	1	2	3	4	5
37. Expanding my education, skills, and interests	NA	1	2	3	4	5
38. Doing things that I enjoy	NA	1	2	3	4	5
39. Doing things with my family	NA	1	2	3	4	5
40. Participation in parent groups or clubs	NA	1	2	3	4	5
41. Traveling/vacationing with my child	NA	1	2	3	4	5

[1] C.J. Dunst, C.M. Trivette, & A.G. Deal (1988). May be reproduced.

BEST COPY AVAILABLE

Family Support Scale [2]

Name _____ Date _____

Listed below are people and groups that oftentimes are helpful to members of a family raising a young child. This questionnaire asks you to indicate how helpful each source is to your family.

Please circle the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. If a source of help has not been available to your family during this period of time, circle the NA (Not Available) response.

How helpful has each of the following been to you in terms of raising your child(ren):	Not Available	Not at all Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
1. My parents	NA	1	2	3	4	5
2. My spouse or partner's parents	NA	1	2	3	4	5
3. My relatives/kin	NA	1	2	3	4	5
4. My spouse or partner's relatives/kin	NA	1	2	3	4	5
5. Spouse or partner	NA	1	2	3	4	5
6. My friends	NA	1	2	3	4	5
7. My spouse or partner's friends	NA	1	2	3	4	5
8. My own children	NA	1	2	3	4	5
9. Other parents	NA	1	2	3	4	5
10. Co-workers	NA	1	2	3	4	5
11. Parent groups	NA	1	2	3	4	5
12. Social groups/clubs	NA	1	2	3	4	5
13. Church members/minister	NA	1	2	3	4	5
14. My family or child's physician	NA	1	2	3	4	5
15. Early childhood intervention program	NA	1	2	3	4	5
16. School/daycare center	NA	1	2	3	4	5
17. Professional helpers (social workers, therapists, teachers, etc.)	NA	1	2	3	4	5
18. Professional agencies (public health, social services, mental health, etc.)	NA	1	2	3	4	5
19. _____	NA	1	2	3	4	5
20. _____	NA	1	2	3	4	5

[2] C. J. Dunst, C. M. Trivette, and A. G. Deal (1988). May be reproduced.

A Self-Check for Enhancing Communication

- ❑ How can I better demonstrate that I listen to and value parents' viewpoints, perceptions, observations, and suggestions?
- ❑ How can I be sure that parents have time for questions?
- ❑ How can I ask hard questions in easy ways?
- ❑ When communication seems to be breaking down, what can I do to initiate remedial actions?
- ❑ How can I ensure that I speak in language and terms that parents understand?
- ❑ How can I more fully support and encourage parents' efforts to learn about their child's condition?
- ❑ What strategies can I use to improve my ability to listen without judgment?
- ❑ What strategies and activities can I use to help family members achieve what they want for their children and themselves?
- ❑ How can I more fully assist families in making informed choices?
- ❑ Do I offer recommendations as options? How can I demonstrate an acceptance of or a respect for parents decisions?
- ❑ Do I recognize that the needs and wishes of the child and family will change over time?
- ❑ How can I communicate with the child to protect and foster a positive self image? How can I encourage and support an older child in understanding the implications of diagnosis and treatment and o managing their own illness or disability?

TIPS

Collaboration and Alliance Building

Parents, physicians, and other healthcare and service providers need to work as partners to meet the needs of children with disabilities and special healthcare needs within the context of their family. Collaboration improves health outcomes for children, as well as the quality of life for the child and the family. The ability to ***mutually*** use each other's knowledge, experience, and expertise is essential for effective collaboration. Effective communication skills are the foundation of these partnerships. In addition, specific skills for collaboration and alliance building are necessary on the part of parents, physicians, and other healthcare and service providers.

"I work collaboratively with families not only because it's the right way to do things, but because it's the most enjoyable, energizing, and satisfying way to provide services."

Wallace, in Bishop, Woll & Arango (1993)

Physicians are needed as active partners in the collaborative process with parents, as are other healthcare and service providers. Parents' knowledge and intuition ***and*** the expertise of physicians and other healthcare providers become the basis on which decisions about a child's care are made. Collaboration and alliance building enhance the family members' ability to take responsibility, feel competent, and act upon their innate sense of what is best for themselves and their child. In fact, collaboration enhances the capacities of all who are involved in providing care to a child with disabilities or special healthcare needs.

New roles and expectations, as well as changes in thinking, beliefs, values, and behaviors are required as parents join physicians and other healthcare and service providers in designing, implementing, and evaluating services for the child and family. These changes may be challenging and difficult for those whose experience is based on more traditional parent-professional relationships. The principles and practices of family centered care provide a place to begin the process of building alliances. This section outlines additional skills for moving toward effective collaborations.

Elements of Collaboration

Collaboration requires mutual respect and the desire to work together to provide the best care possible for all children. In order to build mutual respect, parents, physicians, and other healthcare providers need to see each other as competent. The more competent one feels, the more "collaboratively attractive" one becomes to others. As individuals become collaboratively attractive, their expertise and knowledge are sought and valued. Differences in perspective enhance the quality of care being provided to a child with disabilities. Collaboration and alliance building require an investment in the process by parents, physicians, and other healthcare and service providers. For all involved in the collaborative process, this investment requires:

Shared Responsibility and Ownership

A commitment to the collaborative process is needed, first by finding time and creating energy for all that is required. Collaboration does not occur without thoughtful planning. To take mutual ownership of the process with families, one needs to be willing to change old ways of doing things and old beliefs. This means taking risks, releasing control, and changing how professionals view and interact with family members.

Shared Expectations and Goals

Receptivity and open communication are essential to the collaborative process. When expectations and goals are clearly expressed, work is aimed in a mutually agreed upon direction. This requires that all be flexible, negotiate, and compromise.

Shared Information, Knowledge, and Skills

Trust and respect needs to be developed and nurtured by all members of the collaborative process. Honesty, integrity, and the acknowledgment of each person's strengths and capabilities are necessary when information and expertise are shared. With this, all can

participate in creative problem solving and decision making.

Shared Fears and Frustration

As part of the collaborative process, difficulties, conflicts, and disappointments require discussion. All participants need to show an ability to tolerate differences and disagreements. The collaborative process is impeded when differences and frustrations are avoided. When they are openly shared, goals and solutions are created.

Shared Hopes

Everyone needs to find ways to nurture and sustain the investment, and not allow energy to fade. When each person continually shares their hopes and changing expectations, the process remains alive.

Shared Successes

The family, the child, and the healthcare providers, can share in the success and outcomes of the collaborative process. This builds momentum for the process to continue with the next set of hopes, goals, and expectations.

Creating Partnerships

All of the ***shared elements*** discussed above lead to successful outcomes and also become the benefits of the collaborative process for each of the members involved. Certain values, knowledge, and skills are needed to create partnerships and alliances with families and other healthcare and service providers. One's ability to embody these values and skills will be reflected in each interaction with families about the care of their children. C. J. Dunst, et. al. (1988) describe several help-giving practices that support alliances with families. Opportunities should be created for family members to experience competence and self-efficacy, and to acquire self-sustaining adaptive behaviors. Family members can

be helped to build upon their strengths by allowing them to share the responsibility for identifying problems and concerns, creating solutions, and making the necessary changes to address their needs. Help-giving that does not promote these capabilities in parents may foster dependency and passivity, diminish self esteem, and undermine family competence and control. Partnerships are most effective when everyone ***values*** and ***practices*** positive help-giving and family centered care, and when all recognize that supporting the family creates positive outcomes for the child.

"Partnerships are valued over paternalistic approaches because the former implies and conveys the belief that partners are capable individuals who become more capable by sharing knowledge, skills, and resources in a manner that leaves all participants better off after entering into the cooperative arrangement."

C. J. Dunst, et. al. (1988)

Partnership-Building Skills

- Knowledge of the philosophies and best practices that drive early intervention and special education systems.
- Understanding of what roles and responsibilities the physician and other healthcare providers are expected to assume within the early intervention and special education systems.
- The ability to help parents identify their concerns, priorities, and resources related to their child's care and family functioning.
- The ability to help families match their needs with available resources.
- The ability to provide full, unbiased, and realistic information without extinguishing parents' hopes and dreams for their child.
- The ability to encourage the family's role in decision-making and to create opportunities for parents feel competent in caring for their child.

- The ability to listen to, empathize with, and validate parents' feelings and to recognize parents' needs to also talk with other parents for support, expertise, and resources.
- A desire to communicate with and gather information from other healthcare providers and professionals.
- A desire to advocate for families and to help families advocate for themselves.
- A desire to be accessible, available, flexible, and reliable.

Meetings with Parents

- Provide similar chairs so that all participants have equal levels of eye contact.
- Encourage family members to take notes or tape record the meeting.
- Provide facial tissues.
- Establish uninterrupted time and privacy.
- Encourage the involvement of ***all*** family members and make various time slots available.
- Ensure that key members of the multidisciplinary team are present, understanding that for some families large numbers may be overwhelming and the delivery of information may seem fragmented.
- Share the agenda with parents prior to the meeting and invite their input to the agenda.
- Provide opportunity for discussion and to meet again if needed.
- Include the child once he or she has reached an appropriate age.

  Provide an opportunity for the child to speak confidentially with the doctor, when appropriate.

Resolving Conflict

Disagreements, disappointments, and conflicts will occur. Often conflicts arise because of differing goals and values, misunderstandings, or a lack of information. During conflict and times of stress it is particularly important to sustain the respect and support that has become the basis of the alliance. To do this, efforts must be made to separate the person from the problem; strive for mutual understanding, if not agreement; and be open to negotiation and compromise. Additionally, everyone needs to agree that each member has a right to own ***and*** express his or her own opinions. To resolve conflicts and reach shared decisions, each member is responsible to:

① Maintain focus on the family's concerns and priorities.

② Identify and share their understanding of the disagreement and define the problem from their viewpoint.

③ Listen to the ideas and feelings of others and use effective communication skills.

④ Generate options for solutions that can be win/win/win for the child, family, and physician or healthcare provider.

⑤ Select the best solutions for the child and family.

⑥ Reestablish our goals, action plans, roles, and responsibilities.

⑦ Monitor the action plan as it is implemented.

By successfully managing conflicts and disagreements, professionals can develop more open and trusting relationships with families. Additionally, each person is more likely to have a sense of mutual ownership for decisions and their implementation.

A Self-Check for Collaboration and Alliance Building

- ❑ What more can I do to work ***with*** family members for the well-being of their child?
- ❑ What can I do to ensure that my roles and responsibilities are clear, as well as those of family members and other healthcare providers?
- ❑ Do I truly believe parents are equal partners and have valuable expertise regarding their child?
- ❑ How can I demonstrate that I value parents' comments and insights and make use of their knowledge about their child's total needs?
- ❑ How can I encourage family members to be active participants in the decision making process?
- ❑ Do I recognize that what I perceive as a lack of cooperation or "noncompliant" behavior may mean that a parent's concerns, priorities, and needs are not being addressed? What can I do to address this?
- ❑ Do I measure outcomes in terms of progress and competencies for the child and the family? If not, how can I move toward this practice?
- ❑ In what ways can I enhance my skills for listening responsively, questioning interactively, and responding appropriately to family members?
- ❑ How can I make every effort to work with family members toward solutions and expanding resources?
- ❑ How can I strive to gain mutual understanding with family members so that we can take action as a team and alleviate any problems that arise?
- ❑ Do I continually review, evaluate, and revise action plans with parents?

- ❑ In what ways can I more effectively share with family members the responsibility for planning and implementing care for their child?
- ❑ In what ways can I encourage parents to communicate with other parents?
- ❑ How can I effectively communicate with other healthcare and service providers so that all are as informed as possible?
- ❑ How can I ensure that I am honest about the child's ability and skill levels?
- ❑ Am I effortful in sharing information that will help determine the services and treatments the child and family needs?
- ❑ How can I enable parents to contribute equally to the healthcare plan?
- ❑ How can I communicate openly with parents about disagreements or disappointments?
- ❑ How can I provide clarification, additional information, or help to parents when they are confronted with difficult decisions?
- ❑ How can I help myself to remain focused on the family's priorities and values?
- ❑ What skills can I use to negotiate fairly, without defensiveness and judgment?
- ❑ How can I demonstrate respect for the knowledge, skill, and expertise of all team members?
- ❑ What can I do to ensure that the activities, strategies, services, and treatment plans reflect shared decisions that are based on the family's chosen outcomes and values?

TIPS

Procedures for Early Intervention Referrals

Part H of the IDEA legislation mandates a Comprehensive Child Find System be established. The child find system is designed to ensure that all infants and toddlers who may be eligible for services under Part H are *identified, located, and evaluated*. These efforts are coordinated between the lead agency (in Connecticut, the State Department of Mental Retardation) and all other state agencies responsible for administering education, health, and social service programs such as Maternal and Child Health, Early Periodic Screening, Diagnosis, and Treatment (EPSDT), Head Start, etc.

Identification

Referrals to early intervention services can be made by parents, or, with the family's knowledge and consent, by anyone who has concerns about a child's development, including physicians, other healthcare providers, daycare providers, and other family members.

Procedures exist for use by primary referral sources such as hospitals, prenatal and postnatal care facilities, physicians, parents, daycare providers, public health facilities, and other healthcare providers and social service agencies.

For children ages 3-21

Referrals for evaluation and special education services are typically made to the Director of Special Education or Pupil Personnel Services at the local Board of Education.

In Connecticut referrals are made by calling:

Birth to Three INFOLINE

1-800-505-7000

An early intervention specialist at INFOLINE asks for basic information including the family's name, address, and telephone number, and the reason for referral. The INFOLINE person then contacts the **Regional Family Service Coordination Center** (RFSCC), which provides services for the town in which the family resides. Once the call from INFOLINE has been received at the Regional Family Service Coordination Center, a **service coordinator** is assigned.

Role of the Physician in Identification

- Recognizing factors that place a child at risk for developmental delays.
- Identifying children who have disabilities, developmental delays, or who may be at risk for delay.
- Administering and interpreting developmental screening instruments with all infants.
- Understanding the procedures for referring infants and toddlers to the early intervention system.
- Knowing what community resources are available for infants and toddlers who may or may not be eligible.
- Enhancing alliances and care coordination among secondary and tertiary care settings, risk registries, and other care providers.
- Increasing family awareness of developmental milestones, resources for assessment, the importance of early identification, and the impact of early intervention services.

Service Coordinator

Once the service coordinator is assigned, he or she contacts the child's parents, provides an overview of the early intervention system, and schedules an initial meeting with the family to begin the evaluation and assessment process. The service coordinator is responsible for coordinating all aspects of the early intervention program including: arranging the evaluation and assessment; facilitating the Individual Family Service Plan process; monitoring the delivery of all services across agency lines; coordinating with medical and healthcare providers; and serving as the **single point of contact** in helping parents to obtain the services and assistance they need for their child and the family. Parents have the right to take on the role of service coordinator themselves, if they choose to do so.

Role of the Physician with the Service Coordinator

- Establishing procedures for communication with the service coordinator and other service providers.
- Maintaining ongoing communication with the service coordinator directly and/or through the parents.

Eligibility Criteria

Any child from birth to thirty-six months of age is eligible for early intervention services under Part H if ***either*** of the following conditions are met:

① The child is diagnosed as having an **established condition**. Children with established conditions are automatically eligible for services, although they may not exhibit significant delays at the time of diagnosis. **Established conditions** include but are not limited to:

- Genetic disorders
- Chromosomal syndromes
- Sensory impairments
- Neurological syndromes and conditions
- Conditions related to significant fetal exposure to toxins
- Other physical/medical conditions, atypical developmental patterns, and psychosocial conditions known to result in significant developmental delays

② The child is identified by a multidisciplinary team as exhibiting a **significant developmental delay** in one or more of the following areas:

- Cognitive development
- Physical development, including vision, hearing, motor, and health needs

- Communication, including receptive and/or expressive language development
- Social or emotional development
- Adaptive skills

A significant developmental delay is determined by a score of two standard deviations below the mean in one area of development **or** one and one-half standard deviations below the mean in two areas of development. A child can be referred to the early intervention system **without** a formal diagnosis.

Evaluation and Assessment

The service coordinator works with the family and other service providers to select individuals who will complete a multidisciplinary assessment of the child to determine the nature and extent of his or her needs for services.

The assessment should occur, as much as possible, within the child's natural environments and include input from family members. It should be completed in the child's primary language, using non-biased assessment tools. The evaluation team documents the child's needs in each of the developmental areas including cognitive development, physical development, communication, social or emotional development, and adaptive skills. The child's strengths and competencies should also be noted. In keeping with the practices of family centered care, a **Family Needs Assessment** is also completed, with parent permission. The focus of the family needs assessment is to:

- Elicit parents' concerns and priorities related to their child's development.
- Elicit the desired outcomes or goals for the child's development from the parents and a statement of changes parents would like to see for their child and themselves.
- Identify the family's resources, strengths, and stress levels.

- Identify the parents' needs for support including services for the child, as well as support for themselves, which may include needs such as employment, financial assistance, and other community resources.

If a child is **not eligible** for early intervention programming, the healthcare provider should refer the family to other resources and services within the community. The child's development needs to be monitored in an ongoing manner. Birth to Three INFOLINE offers families the **Ages and Stages (ASQ) Child Monitoring Program**. For children who were referred to early intervention and are not eligible for services, Birth to Three INFOLINE will periodically send parents a questionnaire, which asks them to answer questions about their child's development. Questionnaires are designed to assess the child's development for every four month period up to the age of 48 months. After Birth to Three INFOLINE receives the completed questionnaire, the parents are contacted by phone or mail. Information is provided about whether their child's development is within normal limits, or whether there are concerns warranting another referral to or re-evaluation by the early intervention system.

Role of the Physician in Evaluation and Assessment

- Interpreting diagnostic information and sharing it with the family.
- Obtaining information from other early intervention service providers.
- Presenting information related to the child's medical or healthcare needs to the family and other team members.
- Providing a written medical summary or profile of the child's needs which can be used by parents and service providers.

The Individual Family Service Plan

The **Individual Family Service Plan (IFSP)** is a continuous process, as well as a document representing the child's and family's involvement in the early intervention system. The process involves a team meeting with family members, the service coordinator, the physician, other healthcare providers, the evaluators, and service providers. The IFSP process involves the following steps:

① Review results of the child's evaluations and the family needs assessment

② Develop statements of desired outcomes and priorities for early intervention services, medical or health services, and the family's needs for enhancing the child's development

③ Select specific services to meet desired outcomes and include types of services, providers, duration, frequencies, intensities, methods, locations, and payment responsibilities. Please refer Laws that Serve Children with Disabilities, pages 8-11 for a list of available types of services.

④ Prepare the IFSP document which must include:

- The present level of the child's development in six areas: medical/health, cognitive, communication, gross and fine motor, social or emotional, and adaptive skills.
- A statement of the family's concerns, priorities, and resources.
- A statement of expected major outcomes in the six areas listed in (a) above, including criteria, procedures, and timelines to determine progress and whether modifications or revisions are needed.
- A statement of early intervention services necessary to achieve the identified outcomes, including frequency, intensity, location, method of delivery, and payment responsibility.
- Other needed health, social, and economic services (that are not required by early intervention services) and the steps necessary to assist the family in obtaining these services.
- Projected dates for initiation and anticipated duration of services.

- Steps for supporting the child's transition from the early intervention program to the mandated special education program within the local school district at age three.
- The name of the service coordinator.

Best practices indicate that the child's primary physician should be an active part of the IFSP process. Communication may occur in person at the IFSP meeting, by phone, or by mail. Physicians may be asked to sign the IFSP document to show their agreement with the services that are to be provided and for insurance or Medicaid reimbursement purposes.

Role of the Physician in the IFSP Process

- Discussing with families the value of the IFSP process and early intervention services.
- Assisting families in identifying who they wish to be involved in the IFSP process and in contacting those individuals.
- Assisting the family in their preparation for the IFSP process and providing support throughout the process.
- Participating in the development of the IFSP, as a member of the team.
- Communicating about the child's medical and healthcare needs either directly or through the parents to other team members.
- Helping the IFSP team understand the impact of the child's medical needs on his or her overall development and the implications for program planning and service provision.
- For each healthcare need, documenting healthcare practices and expected outcomes for both home and daycare or school settings.
- Reviewing health related services to ensure they are appropriate and comprehensive.

Provide and Coordinate Services

Best practices in early intervention indicate that services are most effective when they are provided in natural or integrated settings such as the child's home or daycare program. The service coordinator is responsible for scheduling and monitoring the services, as well as maintaining contact with parents, service providers, and the healthcare providers on a regular basis.

IFSP Reviews and Revisions

The IFSP is reviewed at least every six months with regard to the child's development, progress, and outcomes; status of the family's concerns, priorities, and resources; continued eligibility status; and services being provided. Parents, and other team members, with parental permission, can request an IFSP review at any time. A new IFSP is developed annually.

Role of the Physician for Providing and Coordinating Services

- Serving as the care coordinator or liaison regarding the child's healthcare needs, communicating with other healthcare providers, the service coordinator, and other early intervention service providers.
- Monitoring changes in the child's developmental status and medical or healthcare needs and communicating these changes to the family and the service coordinator.
- Reassessing the family members' needs for support and referring them to other community resources.
- Understanding the criteria which might lead to the termination of early intervention services and, if this occurs, supporting family members by referring them to other community resources.
- Providing updated information about the child's healthcare or medical needs, particularly for IFSP reviews.

Transition to the Local Education Authority (LEA)

When a child reaches three years of age, if eligibility requirements continue to be met, services will be provided under Part B of the Individuals with Disabilities Education Act. Part B services pick up where Birth to Three services leave off. This includes preschool through high school special education and other related services for children ages three to 21. Part B services are provided by the Local Education Authority (i.e., the local or regional public school system). The transition from the early intervention system to the special education system needs to be carefully planned.

In the Birth to Three system, transition planning begins **90 days before** a child is to enter the local or regional public school system. Transition planning involves the family, members of the IFSP team, the service coordinator, and representatives from the LEA or school system. The transition process requires a review of the child's present levels of development, progress made during the early intervention program, and eligibility for preschool special education services. In addition, the transition plan includes steps for preparing the child and the family for the change in service provision systems, development of the initial **Individual Education Plan** to begin at age three, and the transfer of all records to the LEA with parental consent.

Role of the Physician for Transition Planning

- Understanding the eligibility criteria and procedures for making referrals to the local or regional public school system for preschool special education services.
- Understanding best practices and the advantages of integrated placements for children with disabilities.
- Participating in the development of the transition plan.
- Providing continued support to the family and resources for ongoing service coordination within the community.
- Working with the LEA to incorporate the child's medical and healthcare needs into the Individual Education Plan.

A Self-Check for Referral Procedures

- ❑ Do I understand the Comprehensive Child Find System in Connecticut?
- ❑ Do I know how to make a referral to the Birth to Three system?
- ❑ How can I become more active in identifying children who are at risk or who have disabilities? What developmental screening procedures do I use in my practice?
- ❑ How can I maintain updated knowledge of the community resources available to infants and toddlers who have disabilities or special healthcare needs?
- ❑ How can I help family members to increase their awareness of developmental milestones and the importance of early identification and early intervention?
- ❑ What procedure can I create for communicating with the early intervention service coordinator?
- ❑ Do I understand the eligibility criteria for children from birth to three years of age to receive early intervention services?
- ❑ How can I more effectively participate in the evaluation and assessment phase of referral? In what ways can I provide information about the child's healthcare needs and help parents to identify their concerns, priorities, and resources?
- ❑ How can I participate in the IFSP process? By communicating with IFSP team members or attending IFSP meetings? How can I ensure that the child's healthcare needs are identified within the IFSP document?
- ❑ How can I ensure that regular updates about the child's healthcare needs are provided to parents and service providers?

- ❑ How can I keep informed about the early intervention services the child is receiving?
- ❑ Am I aware of the transition procedures and eligibility criteria for children who are about to receive services through their Local Education Authority or public school system?
- ❑ Am I aware of best practices in early intervention, and in preschool and special education?
- ❑ How can I ensure that the child's healthcare needs are addressed in the IEP?

TIPS

Community Involvement

Physicians and healthcare providers are essential members of the larger community. Beyond providing healthcare services, communities and families need physicians and other healthcare and service providers to assume broader roles. At community, state, and national levels, involvement in caring for and supporting children with disabilities and special healthcare needs and their families is essential. Professionals are responsible for creating and supporting community based services that enhance the daily lives of and families. Action must be taken to ensure that ***all*** children and families are included or integrated into the community in meaningful and enriching ways.

When designing and implementing community based systems of care, it is necessary to ensure that they are systematically developed, linked, and coordinated. To be certain that these systems of care address the needs of children and families in comprehensive, family centered, and culturally competent ways, professionals and families need to work cooperatively and collaboratively with other service providers and families in the community.

At this time, we will celebrate the new born children in our community. As a community, we recognize that these beautiful children are the seeds of our heritage, fruits of our labor, and the future of our people. We must protect them, we must educate them, and we must love them. As a community, we must share these responsibilities.

Ghanian Ceremony

Community Based Efforts

Healthcare, education, mental health, and social service organizations need to work toward decreasing duplication of efforts, as well as gaps in available resources. This can be accomplished when programs are coordinated, integrated, and collaborative. On the community level this means:

- Clearly identifying services available under each agency or organization.

- Creating information exchange systems across organizations.
- Including service providers and families on planning and policy boards for community organizations.
- Ensuring continuity of care by planning for transitions in services.
- Providing support to personnel in social and educational organizations to acquire skills necessary for integrating children with special healthcare needs or disabilities.
- Building public awareness.
- Creating family support systems.

Public Awareness

To support and integrate children with disabilities and their families in the community, there must be an increase in public awareness about the developmental needs of children, and the specific needs of children with disabilities and their families Community members can be helped to appreciate the mutual rewards of integrating every child and family into community life. Public awareness activities may include:

- Creating outreach efforts to identify children in need of services and to inform community members about the needs of children with disabilities and special healthcare needs.
- Using local employers, businesses, and civic organizations as leaders in increasing public awareness and in recognizing and meeting the needs of children and their families.
- Asking parents to educate the community and service providers about the strengths and needs of their children.

Resource-Based Practices

Carl J. Dunst and his colleagues have developed strategies for identifying and mobilizing community based resources and experiences that can help meet the needs of children with disabilities and their families. A community may be a geographic neighborhood, or a "location" where social, emotional, spiritual, educational, recreational, vocational, or other needs are met. Thus, there are multiple sources of community support that can be accessed to meet the needs of children and families. Community resources may involve specific services, as well as assistance, information, experiences, and any other opportunities that promote the development of children and the well-being of families. Resource-based supports are:

- Community centered, rather than professionally centered.
- Informal ***and*** formal.
- Built around enhancing the strengths and capacities of children and families.
- Broadly available to all members of the community.

The family needs taxonomy discussed on pages 35-36 can be used to help families identify their needs and concerns. The following steps can be used to identify community based resources and sources of to address the needs that families have expressed. This list is adapted from the work of Carol M. Trivette and her colleagues.[2]

① Identify all resources within the community and indicate the actual locations of these resources on a map (community resource mapping).

② Identify the needs and concerns, as well as the strengths of children, individuals, families, and the community as a whole.

---

[2] Trivette, C. M., Dunst, C. J., & Deal, A. G. (Draft). Resource-Based Early Intervention Practices. Chapter prepared for a forthcoming book by S. K. Thurman, F. R. Cornwell, & S. R. Gottwald (Eds.), The contexts of early intervention: Systems and settings. Baltimore: Brookes Publishing Co.

③ Identify the experiences children and families need to gain competence.

④ Identify any concerns or barriers to meeting the needs of children and families.

⑤ Match the identified needs with the resources on the map.

⑥ Find additional resources on the map that can help to eliminate the barriers.

Community Based Supports

Families can be helped to identify the supports that are already in place, and those that are still needed. Often parents are unaware of support systems that exist. Suggestions should be based on the parents' identified needs, priorities, and concerns. Following is a comprehensive list of services that can be made available in any community to support children with disabilities and special healthcare needs and their families.

- ***The Family:*** immediate and extended; spouse or partner; parents; grandparents; in-laws; brothers and sisters; aunts and uncles.
- ***Informal Networks:*** friends; neighbors; parent-to parent networks; parent support groups; co-workers; baby sitters; car pool partners; sibling support groups.
- ***Social Organizations and Associations:*** church or synagogue members; religious or spiritual groups or leaders; artistic organizations; business organizations; charitable groups and drives; civic events; child and family advocacy groups; elderly groups; ethnic associations; fitness groups and sports leagues; special interest clubs; men's and women's groups; self-help groups; outdoor clubs; community service clubs; social cause groups; veteran groups; youth groups; local museums, science centers, and zoos.
- ***Community Programs:*** community colleges; institutions of higher education; social, leisure, and recreational programs; camps; libraries; community

healthcare centers and clinics; police and fire departments; employment agencies and vocational support services; legal assistance agencies; housing assistance; in-home healthcare services; childcare or daycare centers, baby sitter services, and play groups; adult continuing education; volunteer services; respite care; parenting classes; homemaker services; food and nutrition referral resources; the YMCA or YWCA.

- ***Professionals:*** physicians and other healthcare providers; hospital personnel; daycare, school, and early intervention personnel; agency personnel; service providers; service coordinators and case managers; counselors, social workers, and therapists.
- ***Financial:*** healthcare and financial planning programs, insurance reimbursements, entitlement programs (Medicaid, Children with Special Health Care Needs, Social Security Income).
- ***Policy Makers:*** agency directors, school boards, city council, legislators at community, state, and national levels; political organizations.
- ***Other:*** information and referral services (INFOLINE); adaptive equipment loan and exchange programs; interpreting services; transportation assistance; barrier-free community facilities.

Advocacy

Professionals, family members, and other citizens need to closely evaluate public policy and community resources that relate to children with disabilities and special healthcare needs and their families. Advocating for these members of the community involves:

- Accessing funds through grants, private foundations, corporations, public resources.
- Accessing data regarding the utilization of resources.
- Identifying opportunities for providing or receiving training in advocacy skills.

- Communicating with public agencies and legislative bodies.
- Testifying at public hearings.
- Lobbying for policy changes.

Families as Advisors

Community based systems of care and support services are enriched when families provide input. The values, opinions, and perspectives of families that have children with disabilities or special healthcare needs should be major ingredients for shaping policy and program design, and for implementing practices at organizational and community levels. As advisors, family members can directly influence policies, programs, and practices that impact the care and services children and families receive. In this role, family members gain valuable skills, competencies, and confidence. Organizations and services in the community can benefit greatly when family members share their unique perspectives, observations, insights, ideas, and experiences. Parents can help to identify problems, and can be resourceful in creating solutions, even when faced with limited supports and resources.

Family members should be recruited and provided with leadership training so that they gain an understanding of the skills and expectations that go along with their new role. Family members can be involved in an advisory role formally or informally, in an ongoing manner or for a one-time focus group activity. When an organization involves family members in advisory roles, it is beneficial to include those who are new to the early intervention system, as well as those who are currently receiving services, and veterans. Representation should reflect the community in terms of racial, ethnic, socioeconomic, and cultural backgrounds. Finally, more than one family should be invited to participate.

Parents and other family members can serve as advisors in various ways. Some of these advisory roles include:

- Members of task forces, boards of trustees, and advisory boards.
- Program consultants and evaluators.

- Participants in needs assessment processes, quality improvement initiatives, and consumer satisfaction surveys.
- Co-trainers for preservice and inservice sessions, participants and presenters at conferences, and group facilitators.
- Witnesses at hearings.
- Advocates for themselves, and other children and families.
- Members of committees hiring new staff.
- Advisors to medical practices, the educational system, and social service agencies.

Involvement in the community enhances the quality of services and the quality of life for children with disabilities and special healthcare needs and their families. Professionals benefit from the opportunity to learn more about family strengths, resources, and individuality outside of the clinical setting. Community involvement ensures that programs and services truly met the ***self-identified*** needs of families with children who have disabilities and special healthcare needs.

"...families are visionaries. Their dreams are not tied to bureaucratic limitations. Their ideas and hopes for their children, their families, and their communities provide challenge, inspiration, and guidance."

E. Jeppson & J. Thomas (1994)

A Self Check for Community Involvement*

- ❑ How can I demonstrate the belief that parents have unique perspectives and experiences that can enrich our relationship and the care I provide to children?
- ❑ How can I ensure that family members participate in decision making at program and policy levels for my medical practice, community organizations, and agencies?
- ❑ How can I demonstrate the belief that family members bring a critical element to the healthcare team that no one else can provide?
- ❑ In what ways can I invite parents to provide input, feedback, and suggestions about office practices, as well as the care of their child?
- ❑ How can I be more respectful in considering seriously the opinions of family members?
- ❑ How can I encourage family members to look at the bigger picture, beyond their own specific needs?
- ❑ How can I encourage parents to take on advisory roles either in my office practice, or in organizations and agencies within the community?
- ❑ Do I support parents in taking on these advisory roles by providing clear expectations, leadership training, and by delegating responsibilities to them?
- ❑ How can I work with other organizations, agencies, and local businesses to ensure public awareness activities and family support services are available within the community?
- ❑ Hew can I be a better advocate for children and families?

* Adapted from **Essential Allies: Families as Advisors.**

TIPS

Tools for Enhancing Care

To enhance the care provided to children with chronic medical conditions within the primary care setting, W. Carl Cooley, MD has developed suggested guidelines and "office tools" for medical offices. These materials are also useful for providing care to children with disabilities. Dr. Cooley has generously permitted us to share his ideas and materials for this booklet. These materials are provided by the New Hampshire Partners in Health Project, at the Hood Center for Family Support of the Dartmouth Hitchcock Medical Center, Dartmouth, New Hampshire. The New Hampshire Partners in Health Project is funded by The Robert Wood Johnson Foundation and by project #MCJ-337062 from the Maternal and Child Health Program (Title V, Social Security Act).

In keeping with best practices in primary care ***and*** early intervention, these suggestions for enhancing services to children with disabilities and special healthcare needs and their families embrace the philosophies of family centered, community based, coordinated care. Dr. Cooley's model, referred to as **Chronic Condition Management** (CCM), is described as "a specific primary care practice which acknowledges that children with chronic conditions and their families may require more than the usual well child preventive care and acute illness interventions." (Cooley, in press). In the Chronic Condition Management model the child's special healthcare needs are addressed in conjunction with his or her primary pediatric care needs, such as well child care and acute condition care. This model is also extremely useful with children who have disabilities.

When children have complex medical needs, confusion about the roles and responsibilities of the various healthcare providers and other service providers may exist for the providers, as well as the family. Explicit discussions need to take place to address:

- Who will provide which set of healthcare services to the child?
- When is the primary care physician contacted rather than one of the child's specialists?
- How will communication occur between physicians? Between the physician and the school nurse? Between the physician and other service providers?

- Who will coordinate the child's care and treatment plan?

A set of materials and office tools has been developed to enhance services within the primary care setting, collaboration with early intervention service providers and school personnel, and the overall coordination of care. Again, Dr. Cooley has permitted us to share these materials as part of the TIPS booklet. They can be used as examples for creating office tools within any medical practice. **Please do not copy these materials.**

Office Tools

The office tool materials are designed to be color coded and/or have a clearly identifiable design. These include:

- ***External Chart Identifiers:*** Color coded stickers that alert staff that this child is a patient with special healthcare needs (Page 84).
- ***Alert List:*** A list of all patients with special healthcare needs to alert office staff that considerations for specialty scheduling (convenient times, longer appointments) should be given to the family (Page 85).
- ***Coded Phone Message:*** A color coded phone message for use when a parents call about their child (Page 86).
- ***Templates:*** Page forms for referral or progress notes to specialists, informational letters to school nurses, the School/Primary Care Communication Note, and referral to financial support programs (Pages 87-89).
- ***Resource Information:*** A notebook with information about community and regional resources for families including social service agencies, financial support programs, local parent support groups, etc.

Care Coordination Tools

These care coordination tools are designed to guide the family and the healthcare provider through an office visit so that all of the concerns, priorities, and needs for resources related to the child's care are addressed.

- ***Agenda - Primary Care Office Visit:*** An attachment to the chart to remind the healthcare provider(s) to ask family members about their needs for: information about their child's care; printed educational materials; additional supports and resources; or communication with other healthcare or service providers (Page 90).
- ***List of Healthcare and Other Service Providers:*** A single page sheet in the file that serves as a reference to all other services and providers involved in the child's care and supporting the family (Page 91).
- ***Care Planning Sheets:*** The first page provides space to indicate family concerns, healthcare provider's concerns, medical updates, information about other supports in the child's and family's life, and financial needs. The next two pages provide space for indicating tasks that need to be accomplished, who is responsible for following through with the tasks, and additional care notes (Pages 92-93).
- ***Critical Aspects of Care Guide:*** Single page "Healthwatch" guidelines for the care of various chronic conditions (Page 94).

Child Care Tools - A Parent's Notebook

This notebook is given to parents of children with disabilities and special healthcare needs to enhance their participation in the management of their child's care. It is designed to help parents organize their contacts with various healthcare providers and other service providers and to record concerns, questions, and changes needed in their child's care. The contents of the parent's notebook include:

- ***Care Providers:*** Phone numbers and addresses of the primary care physician, other healthcare providers and specialists, and other service providers.
- ***Medical Care Details:*** Information about medication and dosage, tests completed and results, family and child medical history, immunization records, and medical appointment notes.
- ***Personal Notes:*** Suggested questions that parents may ask about services for their child, scheduling considerations, illnesses, general check ups, medication, tests, referrals to specialists, surgery and hospitalization, and the child's questions and concerns.
- ***Care Needs:*** Emergency plans, emergency contacts and phone numbers, baby sitter's guide, information for caregivers, daily routines, and special instructions.
- ***School Issues:*** Suggestions for contacting school personnel, preparing for meetings, discussing the child's needs, developing an action plan, communicating about the child's special healthcare needs and the impact in school, physical education activity guide, forms for communication between school personnel and the physician, permission to disseminate medication at school and to administer specialized healthcare procedures, and documentation of training for staff on specific healthcare procedures.
- ***Information and Resources:*** A list of organizations, contact persons, services they provide, and other information related to the needs of the child and the family.
- ***Business:*** Information about health insurance, Medicaid, and other entitlement programs.

Dr. Cooley suggests that the Chronic Condition Management model be used if a child's disability or healthcare needs significantly impact daily living, family life, school performance, or the child's development. This model of primary care may also be helpful when a child requires ongoing specialty care, the involvement of

multiple service providers and agencies, or during crises or times of significant family stress related to the child's healthcare status.

Once the decision is made to use this care model with a child and his or her family, it should be implemented in an organized manner. The model needs to be discussed with the parents (and the child, if appropriate). Specifically, parents and physicians need to clarify expectations, roles, and responsibilities. Parents should be given the name of a primary contact person within the office. The child's chart should be set up and marked with the chart identifiers described above. Dr. Cooley outlines suggestions for periodic visits at the primary care level to monitor children with special healthcare needs. During these monitoring visits the following should be addressed:

- Identify the parents' current concerns.
- Identify the healthcare provider's current concerns.
- Assess changes since the previous visit.
- Assess the current health status of the child.
- Review outcomes of any specialty contacts or visits.
- Review the impact of special healthcare needs on the child's life, and school performance, family life, emotional coping, financial resources.
- Determine if parents need additional educational materials, resources, referrals.
- Determine the need for further consultation with specialists, other service providers, or school personnel.
- Review and revise care priorities and action plans.

A Self-Check for Enhancing Care

- ❑ What system can my office develop for identifying the charts of children with special healthcare needs?
- ❑ How can I ensure that office staff are aware of the families who may need special scheduling considerations?
- ❑ What can my office do to develop standard formats for consultations or communications with other healthcare providers, daycare or school personnel, and other service providers?
- ❑ How can my office maintain lists of various resources for information and community support available to parents?
- ❑ How can I keep track of others who are involved in a child's care? Is a list of all other healthcare and service providers attached to the child's chart?
- ❑ What format can I develop for recording parent concerns, as well as my concerns for the child's care and for planning how those concerns will be addressed?
- ❑ How can my practice help family members organize the often overwhelming amount of information they need to have about their child?
- ❑ What other things can be done in my office to enhance the care provided to children with disabilities and special healthcare needs?

The following section is a set of sample materials from Dr. W. Carl Cooley and the New Hampshire Partners in Health Project, which is funded by The Robert Wood Johnson Foundation and by project #MCJ-337062 from the Maternal and Child Health Program (Title V, Social Security Act). These samples are provided as suggestions that can be used to develop office procedures for enhancing the care provided to children with disabilities and special healthcare needs and their families. **Please do not duplicate these materials.**

External Chart Identifiers
(Color Coded)

Chronic Condition Management
In the Primary Care Setting

New Hampshire Partners In Health
Office Partners Project

CHRONIC CONDITION MANAGEMENT IN PRIMARY CARE

Notes/Contact:

_____

_____

_____

NH Partners In Health Office Partners Project

CHRONIC CONDITION MANAGEMENT in PRIMARY CARE

FAMILIES FOLLOWED (ALERT LIST)

1

2

3

4

5

6

7

8

9

10

11

12

13

14

15

NH Partners In Health
Office Partners Project

Coded Phone Message

PHONE MESSAGE

FOR _____ **DATE** _____ **TIME** _____

FROM _____ **RE:** _____

PHONE #: _____ **BEST TIME:** _____

MESSAGE: _____

_____

_____

CHRONIC CONDITION MANAGEMENT in PRIMARY CARE
NEW HAMPSHIRE PARTNERS IN HEALTH OFFICE PARTNERS PROJECT

Referral for Specialty Consultation

Child's Name
Date: **Specialist referred to:**

Clinical Problem:

Specific Questions I need answered:

Parent/Child Concerns:

Ongoing Care desired:

__ Consultation without ongoing subspecialty care
__ Phone discussion about specific shared roles in disease management
__ Chronic condition management locally between subspecialty visits
__ Subspecialty management of all aspects of the chronic condition with acute and primary care locally.

Easiest time to contact me:

I would appreciate receiving a recent update or review article on:

Doctor's name: _____
Clinic title: _____
Street address: _____
Town, state, zip code: _____
Telephone number: _____

Enclosed: __ office/hospital progress notes
__ lab results
__ X-rays (___ family will hand carry)

NH Partners in Health
Office Partners Project

Tools for Enhancing Care

Communication with School or Daycare Program

To: _____ Date: _____

Child's Name: _____

Date of Birth: _____

The child named above is a patient of mine whose parent(s) have asked me to notify school personnel that he/she has a chronic medical condition which may at times affect attendance, performance, or health at school. Though specialists may be involved in the management of this condition, I would like to be your primary resource regarding the health or medical management of this student. Please feel free to contact _____ at my office with any questions regarding this child's needs at school.

Chronic medical condition(s) affecting this child:

_____

_____

Current medications and my orders if administration at school is needed:

_____

_____

_____

Restrictions, suggestions, or special instructions:

_____

_____

_____

If you need further information about this child's chronic medical condition to assist with meeting his/her educational needs please let me know. His/her parent(s) or legal guardians have given consent by their signature below for you to contact me regarding school-related issues and to inform me if his health is seriously impacting on school attendance or performance.

Sincerely,

I hereby consent to communication and exchange of information regarding my child _____ between _____ and my child's school principal, school nurse, or classroom teacher(s) at _____ school regarding health issues that may impact on his/her performance at school.

_____ _____

parent's or guardian's signature date

NH Partners in Health Office Partners Project

SCHOOL/PRIMARY CARE COMMUNICATION
(Postcard Format)

TO _____

FROM _____ PHONE _____

I am the primary care doctor/school nurse for _____

Office/School _____

I have a question/concern/about _____

_____

_____

Please call me as soon as you can @ ( ) _____ or ( ) _____

Best Time _____

Other _____

New Hampshire Partners in Health Office Partners Project

Please respond, fold & return!

_____

_____

_____

_____

_____

_____

_____

_____

AGENDA: Primary Care Office Visit

Name _____ **Date** _____

Any questions about the following?

- ☐ Medication/Treatments
- ☐ School Needs
- ☐ Med Education-Child/Family
- ☐ Financial
- ☐ Family Support
- ☐ Specialty Care
- ☐ Home Health/Community Services
- ☐ Other _____

FAMILY ISSUES AND CONCERNS THIS VISIT:

_____

_____

_____

PRACTICE ISSUES AND CONCERNS THIS VISIT:

_____

_____

_____

Chief Complaint:

Type Visit:

Care Coordination:

New Hampshire Partners in Health Office Partners Project

List of Healthcare and Other Service Providers

Child's Name: _____ **DOB:** _____
Dx: _____

Health Care:	Name/Location	Phone #	Fax #	Referral Date
Specialists:				
Special clinics: (coordinators)				
Other:				

School Services:	Name/Location	Phone #	Fax #	Effective Dates
Early intervention:				
School attending:				
School principal(s):				
Classroom teacher(s):				
School nurse(s):				
Spec. ed. coordinator:				
Other personnel:				

Community services:	Name/Location	Phone #	Fax #
Family support coordinator:			
Visiting nurse:			
Mental health provider:			
HMO/Insurance contact:			
DCYF case worker:			
Other service providers:			
Informal supports: (minister, friend, etc.)			

Chronic Condition Management in Primary Care
Care Planning

Parent's Names _____/_____

Child's Name _____ Diagnosis(s) _____

Phones (H) _____/_____ (W) _____/_____

Best Time/Place To Call _____ FAX # if available _____

CCM Monitoring: Questioning & Interventions in the following areas:

	Date: /	/	/	/
Family's #1 Issue				
Health Provider's #1 Issue				
Chronic Condition Update (meds, acute episodes, etc.)				
Child's Life/ Recent Accomplishments:				
Family Life				
Comm/Family Support Issues				
Financial Issues (insurance, SSI, etc.)				
School Needs				
Specialist Contacts				
Patient Education/ Self Care				
Other				

PARENT NOTEBOOK GIVEN (DATE) _____ OFFICE CONTACT PERSON _____

New Hampshire Partners in Health Office Partners Project

Chronic Condition Management in Primary Care
Next Steps Needed

Child's Name _____ Phone Number _____

Diagnosis(s) _____

Date	Task	Who	Notes	Date Done

Next appointment needed:

Next CCM monitoring visit:

Review Date / / / / / /

New Hampshire Partners in Health Office Partners Project

Tools for Enhancing Care

FIGURE 2 Healthwatch for the Person with Down Syndrome Adapted with permission from Crocker and Rubin (1989)

CONCERN	CLINICAL EXPRESSION	WHEN SEEN	PREVALENCE	MANAGEMENT
congenital heart disease	complete AV canal septal defects mitral prolapse	newborn or first six weeks; later for mitral prolapse	40-50%;	Pediatric cardiology consultation; echocardiogram; surgery; dental prophylaxis
hypotonia	reduced muscle tone; increased range of joint movement; motor function problems	throughout life; tends to improve with age	100%	guidance by physical therapy early intervention program
delayed growth	usually near or below third percentile of general population for height	throughout life	100%	nutritional support; DS growth charts check heart/thyroid; ? growth hormone in future
developmental delays	some global delay, degree varies; specific processing problems; specific language delay	first year; monitor throughout life	100%	early intervention individual educational plan language intervention
hearing problems	middle ear problems (fluid and infections) sensorineural hearing loss	screen in first six months; recheck annually	50-70%	audiology, tympanometry ENT consultation myringotomy tubes if needed
vision problems	refractive errors strabismus cataracts	eye exam in 1st month; then annually	50% 35% 15%	pediatric opthalmologic consultation and appropriate treatment
cervical spine problems	atlanto-axial instability skeletal anomalies may cause spinal cord injury	initial x-ray screen at 3 years old	15%	orthopedic; neurology; neuro-surgery; avoid high risk activity; surgery if spinal cord compression
thyroid disease	hypothyroidism (rarely hyper-)	some congenital; check annually	15%	endocrinology consultation; replacement therapy
overweight	excessive weight gain	late preschool; adolescence/adult life	common	life style changes around food/exercise; check thyroid function; ? depression
seizure disorder	generalized or myoclonic; hypsarrhythmia	any time	5-10%	neurology consultation, EEG, medication
emotional problems	behavioral changes; depression	adolescence; young adult	common	inclusive education; counseling; support during transition from school to work

variable occurrence of: gastrointestinal anomalies; Hirschsprungs; leukemia; alopecia areata; diabetes; sleep apnea; hip dysplasia

BEST COPY AVAILABLE

References and Resources

American Academy of Pediatrics. (1988). Proceedings from a National Conference on Public Law 99-457: Physician Participation in the Implementation of the Law. Washington, DC: American Academy of Pediatrics.

American Academy of Pedicatrics, Committee on Children with Disabilities (1992). Pediatrician's role in the development and implementation of an Individual Education Plan (IEP) and/or an Individual Family Service Plan (IFSP). Pediatrics 89: 340-342.

American Academy of Pediatrics, Ad Hoc Task Force on Definition of the Medical Home. (1992). The Medical Home. Pediatrics 90: 774.

American Academy of Pediatrics, Pediatric primary health care provider addendum: Addemdum to the medical home statement. (November, 1993). AAP News.

American Academy of Pediatrics. Medical Home Program for Children with Special Needs. (1995). The medical home and early intervention: Linking services for children with special needs. Elk Grove Village, IL.

Bishop, K. K., Woll, J., & Arango, P. (1993). Family/professional collaboration for children with special health needs and their families. Burlington, VT: University of Vermont, Department of Social Work, Family/Professional Collaboration Project.

Blackmand, J. A. (1991). The pediatrician and the interdisciplinary process. Exceptional Children 48:306-315.

Brewer, E. J., McPherson, M., Magrab, P., & Hutchins, V. (1989). Family centered, community based, coordinated care for children with special health care needs. Pediatrics 83:1055-1060.

Bureau of Maternal and Child Health, American Academy of Pediatrics. (June, 1989). Establishing a medical home for children served by Part H of Pulbic Law 99-457. Washington DC: Georgetown University Child Development Center.

Cooley, W. C. (1992). On golden pond. Medical Home Newsletter 2, 9-10.

Cooley, W. C. (in press). Community outreach - extending and enhancing care where families live. In S. L. Hostler, (Ed.), Family-centered care: An approach to implementation. Washington, DC: U.S. Department of Health and Human Services.

Cooley, W. C. (in press). Changing care in private practice - Chronic Condition Management in the primary care setting. In Ross Roundtable on Chronic Illness in Children.

Coury, D. L. (1990). Training physicians for increased involvement with children with special needs. Infants and Young Children 2:51-57.

Cross, T. L., et. al. (1989). Towards a culturally competent system of care, Volume I. Washington, DC.: Georgetown University Child Development Center, CASSP Technical Assistance Center.

Darling, R. B., & Peter, M. I. (Eds.). (1994). Families, physicians, and children with special health needs: Collaborative medical education models. Westport, CT: Auburn House.

Desguin, B. W. (1988, February). Preparing pediatric residents for the primary care of children with chronic illness and their families: The chronic illness teaching program. Zero to Three, 7-10.

DiVenere, N., Frankowski, B., & Stifler, D. (1991). The medical education project: A shared learning experience-Incorporating the principles of family-centered care in physician education. Medical Home Newsletter 4(2):2, 5-8.

Dunst, C., Trivette, C., & Deal, A. (1988). Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline Books.

Dworkin, P. H., Shonkoff, J. P., Leviton, A., et. al. (1979). Training in developmental pediatrics. American Journal for Disabled Children, 133, 709-712.

Epstein, S. G., et. al. (1989). Enhancing quality: Standards and indicators of quality care for children with special health care needs. Boston, MA: New England Serve, A project administered by the Massachusetts Health Research Institute, Inc.

Gallagher, F., & Garland, C. (1994). In R. B. Darling & M. I. Peter (Eds.). Families, physicians, and children with special health needs: Collaborative medical education models. Westport, Connecticut: Auburn House.

Green, M. (Ed.). 1994). Bright futures: Guidelines for health supervision of infants, children, and adolescents. Arlington, VA: National Center for Education in Maternal and Child Health.

Guralnick, M. J., Bennett, F. C., Heiser, K. E., & Richardson, H. B. (1987). Training future primary care pediatricians to serve handicapped children and their families. Topics in Early Childhood Special Education 6:1-11.

Guralnick, M. J., Richardson, H. B., Jr., & Heiser, K. E. (1982). A curriculum in handicapping conditions for pediatric residents. Exceptional Children 48:338-346.

Haggerty, R. J. (1974). The changing role of the pediatrician in child health care. American Journal for Disabled Children, 127, 545-549.

Healy, A., & Lewis-Beck, J.A. (1987). Improving health care for children with chronic conditions: Guidelines for physicians. Iowa City, Iowa: The University of Iowa, Division of Developmental Disabilities.

Howard, J. (1982). The role of the pediatrician with young exceptional children and their families. Exceptional Children, 48, 316-322.

Jeppson, E. S., & Thomas, J. (1994). Essential allies: Families as advisors. Bethesda, MD: Institute for Family-Centered Care.

Koop, C. E. (1987). Surgeon general's report: children with special health care needs - Campaign '87 - Commitment to family-centered, coordinated care for children with special health care needs. Washington, DC: US Department of Health and Human Services.

McGonigel, M. J., Kaufmann, R. K., & Johnson, B. H. (Eds.). (1991). Guidelines and recommended practices for the individualized family service plan (2nd ed.). Bethesda, MD: Association for the Care of Children's Health

McInerny, T. (1984). Role of the general physician in coordinating the care of children with chronic illness. Pediatric Clinic of North America 31, 199-210.

National Center for Networking Community-Based Services. (1989). Establishing a medical home for children served by part H of Public Law 99-457. Washington, DC: Bureau of Maternal and Child Health and Resources Development and The American Academy of Pediatrics.

Peter, M. I. (1989). The pediatrician and the new morbidity, module III: The pediatrician and family centered care. Honolulu: Hawaii Medical Association.

Peter, M. (1992). Combining continuing medical education and systems change to promote physician involvement. Infants and Young Children 4:53-62.

Powers, J. T., & Healy, A. (1982). Inservice training for physicians serving handicapped children. Exceptional Children 48:332-337.

Scott, F. G., Lingaraju, S., Kilgo, J. L., Kregel, J., & Lazzari, A. (1993). A survey of pediatricians on early identification and early intervention services. Journal of Early Intervention 17:129-138.

Seklemian, P., Scott, F., & Garland, C. (1993). Caring for infants and toddlers with disabilities: A self-study manual for physicians. Lightfoot, VA: Child Development Resources.

Sharp, M. C., & Lorch, S. C. (1988). A community outreach program for pediatric residents and medical students. Journal of Medical Education 63:316-322.

Shonkoff, J., Dworkin, P., Leviton, A., & Levine, M. (1979). Primary care approaches to developmental disabilities. Pediatrics 64:506-514.

Solomon, R. (1995). Pediatricians and early intervention: Everything you need to know but are too busy to ask. Infants and Young Children, 7(3): 38-51.

Teplin, S. (1988). Preparations of physicians to work with handicapped infants and their families: Issues, needs, and future directions. North Carolina: University of North Carolina, Clinical Center for the Study of Development and Learning.

The Task Force on Pediatric Education. (1978). The future of pediatric education. Evanston, Illinois: American Academy of Pediatrics.

Wachtel, R. C., Grossman, L., Hyman, S. L., & Kappelman, M. (1992). Helping future pediatricians to know and understand: Preservice education for professionals who care for children with chronic and disabling conditions.

In R. B. Darling & M. I. Peter, (Eds.). Creating family-professional partnerships: Educating physicians and other health professionals to care for children with chronic and disabling conditions. Conference proceedings. Honolulu: Hawaii Medical Association.

Weinberger, H. L., & Oski, F. A. (1984). A survey of pediatric resident training programs 5 years after the Task Force Report. Pediatrics 74:523-526.

Wender, E. H., Bijur, P. E., & Boyce, W. T. (1992). Pediatric residency training: Ten years after the Task Force Report. Pediatrics 90:876-880.

Other Products

The following products have been developed as part of the Physicians Training Project and may be obtained by contacting the Division of Child and Family Studies as indicated on the inside cover of this booklet.

Early Intervention and Special Education in Connecticut - The Physician's Role A set of nine training manuals designed to be used with medical students and pediatric or family practice residents. Each manual contains objectives, background information, a family study, discussion questions and answers, and a case resolve. The nine manuals cover the areas of Family Centered Care, Education Law, Research Efficacy, Role of Other Disciplines, Curriculum Development, Natural Instructional Environments, Service Coordination, Team Process, and Collaborative Consultation.

A Physician's Reference - Services for Children with Disabilities and Their Families A booklet of fact sheets describing programs and agencies in Connecticut that provide a variety of services and supports to children with disabilities and their families. Each description includes general information about the

program, who is eligible, what services are provided, and whom to contact for further information or to make referrals.

A Family's Reference - Services for Children with Disabilities and Their Families A booklet of fact sheets describing programs and agencies in Connecticut that provide a variety of services and supports to children with disabilities and their families. Each description includes general information about the program, who is eligible, what services are provided, and whom to contact for further information or to make referrals.

Working Effectively with Families and Their Children with Disabilities A curriculum guide designed to enhance the clinical rotation experience of pediatric residents who are working with children with disabilities and special healthcare needs. This curriculum incorporates a protocol for a home visit and a day care or school visit, as well as self-study manuals on Family Centered Care, Education Law, and Team Process.

Notes